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Living with COVID-19: A phenomenological study of hospitalized patients involved in family cluster transmission

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Living with COVID-19: A phenomenological study of hospitalized patients involved in family cluster transmission

Abstract

Objectives: To describe experiences of hospitalized patients with COVID-19 following family cluster transmission of the infection and the meaning of these experiences for them.

Design: A descriptive phenomenological design was used to construct themes depicting patients' experiences of living with COVID-19.

Setting: This study was conducted in a major teaching hospital in Wuhan, China in March, 2020.

Participants: Fourteen patients involved in family cluster transmission of COVID-19 were recruited into the study. The participants consisted of seven males and seven females. Data were collected through semi-structured, in-depth, face-to-face interviews. Interviews were transcribed verbatim and analyzed using Colaizzi's approach.

Results: Six themes emerged from data analysis during two distinct phases of patients going through COVID-19: the early outbreak phase and the later hospitalization phase. Early in the outbreak, patients experienced life imbalances between individual wellbeing and family responsibilities. While facing widespread prejudice and rejection, patients dealt with the heavy toll that the illness had left on their body and mind. After being hospitalized, patients described feelings of living with uncertainty, sadness, fear of death, and concerns about family, while simultaneously hoping for a better life after recovery.

Conclusions: Our findings suggest that living with COVID-19 is an emotionally and physically challenging experience for patient participants in the study. Psychological evaluations need to be routinely carried out with patients in a public health crisis. Interprofessional and

interorganizational collaborative efforts should be made to examine the physical and psychological sequelae of COVID-19, as well as investigate outcomes of existing intervention programs.

Strengths and limitations of this study

- As patient direct caregivers, we conducted an inquiry into hospitalized patients' experiences of living with COVID-19 following family cluster transmission of the infection amidst the outbreak in Wuhan, China.
- Our findings intend to inform the development of specific intervention programs to prevent survivors from experiencing long-term physical and psychological consequences of the outbreak.
- This inquiry into a new phenomenon can generate evidence-based information that might influence the development of guidelines on care provision for patients with COVID-19 in other countries whose outbreak occurred after China.
- Our sample population consisted of patients with mild to moderate clinical symptoms, which limits the transferability of our findings to COVID-19 patient population at large.

Introduction

In December, 2019, a novel coronavirus disease later known as COVID-19 emerged in Wuhan, the capital city of Hubei province in China. Within one month, the deadly viral disease spread from a single city to the entire country.[1] Because of its strong human-to-human transmission ability, COVID-19 soon became a global public health concern.[2] On March 11, 2020, the World Health Organization officially declared COVID-19 a global pandemic.[3] In the meantime, global collaborative research efforts have been made to share real-time data combating the pandemic. The pertinent research on the viral disease concerning its clinical and epidemiological features and possible transmission routes are ever-expanding.[4 5] Even the lived experiences of frontline healthcare workers caring for patients with COVID-19 have started to emerge.[6] However, apart from Sahoo and colleagues,[7] remarkably little is known about the real-life experiences of those affected by the illness. In Sahoo et al.'s study, narrative summaries were reported on three patients' experiences of living with COVID-19 infection. The case descriptions revealed highly distressing mental health issues that patients experienced on hospital isolation units. Noteworthy, Sahoo et al.'s report has primarily focused on the mental health issues that patients had gone through in the hospital. Furthermore, the case study approach adopted in Sahoo et al.'s study might have failed to uncover patients' thoughts, feelings, and behaviors in response to the illness.

The adverse impact of past epidemics such as Severe Acute Respiratory Syndrome (SARS), Middle East respiratory syndrome (MERS), and Ebola hemorrhagic fever on survivors' physical and mental health has been well documented. In a critical review of 20 original studies pertaining to the psychological experiences of SARS survivors, Gardner and Moallef revealed prominent psychological sequelae such as fear, emotional distress, and posttraumatic stress symptoms experienced by SARS survivors in the early acute and later recovery stages of the illness.[8]

Similarly, survivors of MERS reported painful experiences of social prejudice and stigmatization as well as reduced quality of life years after the outbreak.[9 10] In reviewing some recent literature on the Ebola outbreak, physical and mental health has also taken a big toll on the patients,[11 12] with many survivors of Ebola facing significant challenges reintegrating into their social and professional life after hospital discharge.[13]

Although COVID-19 is considered to be much different from past outbreaks in its global impact, the existing literature indicates that patients' emotional responses and perspectives need to be studied to glean evidence for the development of interventions to address individuals' at-risk experiences in the long run. Of note, while patients with COVID-19 are infected individuals, many of them assume the dual role of family members of the infected and even the deceased. Early in the outbreak of the pandemic, many case studies reported in China have demonstrated consistent evidence on rapid transmission of COVID-19 in the form of family clusters.[4 5] Consequently, extraordinary public health measures and education campaigns have been implemented to reduce further spread of the virus within China and elsewhere.[2]

Taken together, the research studies concerning COVID-19 to date have tended to focus on the biomedical aspects of the illness or the experiences of healthcare workers. To our best knowledge, little research has been done to explore patient experiences in the mid of COVID-19. A better understanding of patients' lived experiences might help to inform local and national efforts to strengthen service provision for patients and their families during and after the outbreak. Healthcare workers will also benefit from the perspectives of the recipients of their care in preparation for future pandemics.[12] Given that COVID-19 is transmitted quickly within family clusters, we endeavored to explore the experiences of patients originated from family cluster contexts to clarify the individual and family impact of the outbreak. The central research question guiding the study was: “What is the experience of living with COVID-19 following family cluster transmission of the illness?”

Methods

Design

Descriptive phenomenology was the research design selected for the study. Husserl’s philosophical underpinnings are foundational to descriptive phenomenology. For Husserl, the aim of phenomenology is to arrive at an essential understanding of human consciousness through describing features common to all people who have the experience.[14] Descriptive phenomenology is most suitable to make an inquiry into universal aspects of a phenomenon that have never been conceptualized in prior research.[15] Living with COVID-19 is a new phenomenon, and existing literature on the outbreak does not readily inform us about the complexity and intricacies of patients’ emotional responses to this unprecedented crisis.

Inherent in descriptive phenomenology is the principle of bracketing by holding in abeyance preconceived beliefs and opinions about the phenomenon under study.[16] Through bracketing, the essence of the phenomenon emerges from the perspective of those experiencing it. Bracketing for this study was accomplished through reflexive journaling. Throughout the study, reflexive notes regarding preconceptions and presuppositions, experiences of the research team caring for patients with COVID-19, together with thoughts after interviews were recorded and discussed among members of the research team. Furthermore, reflexive notes were revisited prior to each interview and during data analysis to ensure the interviewer-imposed assumptions did not take precedent over the participants’ described experiences.

Setting and participants

The study was conducted in a large teaching hospital in Wuhan, China. Our research team primarily consisted of nurses who were deployed to Wuhan from another teaching hospital in Hunan province to work intensively with this patient population. Following our deployment to Wuhan, members of the research team were assigned to work in a 55-bed occupancy general isolation ward where patients were admitted with mild to moderate COVID-19 symptoms for isolation or transferred from intensive care units (ICUs) waiting for discharge. All patients on the general isolation ward were able to perform activities of daily living independently or with minimal assistance. The patients were free to move around the public areas on the isolation ward such as hallways and tea rooms while wearing face masks. While working with patients closely on the isolation ward, members of the research team were constantly intrigued by the patients' needs to share their stories with frontline healthcare workers, particularly nurses. Initially, we were concerned about our ability to meet the phenomenon completely unprejudiced. But the merits of conducting this research outweighed any potential harm to scientific rigor. Finally, we decided to take this unique opportunity and apply rigorous research methods to investigate the lived experiences of those patients that we cared for.

To concentrate on our clinical responsibilities and meet the phenomenon as free as possible, we assigned specific nursing staff members to recruit participants and conduct interviews. The sample criteria required that the patient was involved in family cluster transmission; was willing and able to articulate his or her experience; and had stable physical conditions (e.g. Oxygenation Index ≧300mmHg). In addition, healthcare providers' opinions were sought to determine the appropriateness of patients' participation in the study. Participants were recruited using a combination of convenience, snowball, and purposive sampling strategies. Our first three participants responded to the research flyers posted in the public areas of the general isolation ward. The rest of the participants were recruited through snowball sampling. To maximize the sample variations, we purposively took into consideration of the index case in the family, the number of patients in each family cluster, and the number of deaths in the family. In addition, we purposively recruited all participants from different family clusters attempting to generate rich perspectives because of the exploratory nature of the study. Patients' experiences from the same family clusters are distinctive ones with an additional layer of complexities and dynamics, warranting a separate study of this potentially vast population.

Ethics

Approval to conduct this study was given by the Institutional Review Board from the hospital where the study was conducted (stamped and approved) and the hospital where the researchers were deployed from (No: 2020-S333). All participants were informed of the voluntary nature of the study, and they were allowed to withdraw from the study at any time without any consequences to the care provided to them. Because of the sensitive nature of the research topic, participants may be referred to a mental health counsellor in the hospital if they showed strong emotional responses to the interview questions. The referral would only be made with individual participant's permission. Furthermore, the interviewer showed participants empathy throughout the interviews and constantly bracketed out her personal feelings. Written consent was obtained from all participants before the start of the interview. Confidentiality was ensured by assigning a unique participant number to replace participants' names on the transcripts. All electronic data were kept in password-protected files on computers, which were in a secure place and only accessed by members of the research team. The raw data (e.g. reflexive notes, audio-recordings) were stored separately in a locked facility.

Data collection

Semi-structured, in-depth, face-to-face interviews were conducted between March 1 and March 25, 2020. All interviews were conducted in a private, quiet conference room on the isolation ward to ensure privacy, participant comfort, and to promote open sharing of experiences. During the entire interview, both the interviewer and the interviewee wore new face masks and sat apart from each other with six feet social distance. Each interview lasted between 40 and 60 minutes, and it was audio-recorded. Demographic information about each participant was obtained at the start of the interview. Interviews began with a broad open-ended question asking, “What is it like to be a patient living with COVID-19?” Prompts from the interview guide were used to encourage participants to elaborate on their experiences (Table 1). Having daily interactions with patients on the unit helped the research team to develop interview questions that were most pertinent to patients’ experiences living with COVID-19.

To separate our researcher and caregiver roles, we recruited a Master-degree prepared nursing staff member who was not directly affiliated with the study to conduct all interviews. Prior to the conduct of patient interviews, the nursing staff organized practice interviews with a qualitative researcher on the research team to validate appropriate interview skills and bracketing were implemented throughout the investigation. The audio-recording was transcribed verbatim by two members of the research team within 24 hours, and the interviewer’s reflexive notes were discussed among members of the research team. The interviews and original transcripts were originally recorded in Chinese. All quotations were translated into English language by the first author (female) and back translated into Chinese language by the co-first author (female). Data collection continued until data saturation had been achieved as evidenced by redundant information kept emerging.

Data analysis

All audio and written data were imported into NVivo 12 (QRS International) to assist with data management and categorization. The analysis based on Colaizzi's method included the following seven steps: 1) Reading all the transcripts three to five times to gain an understanding of meanings conveyed; 2) Reviewing each description and extracting significant statements; 3) Formulating meanings for these significant statements; 4) Categorizing the formulated meanings into clusters of themes; 5) Integrating the findings into an exhaustive description of the phenomenon; 6) Returning the exhaustive description to participants for validation of feelings, and 7) Incorporating any relevant new data into final description of the essence of the phenomenon.[17] In the present study, 150 significant statements were extracted from the transcribed interviews. These significant statements were then transformed into 42 formulated meaning units. These formulated meaning units were later grouped into two main categories with six distinct themes discussed in the findings. Initial data coding was completed by two members of the research team. Nevertheless, there were ongoing discussions among all research team members about the analysis of the data, and the research team reached an agreement on final findings presented in this paper. Throughout the paper, we followed the Consolidated Criteria for Reporting Qualitative Research (COREQ).[18]

Trustworthiness

To enhance trustworthiness of the study, we followed Lincoln and Guba's definitions for the establishment of rigor in qualitative research.[19] To ensure credibility, bracketing was implemented throughout the research process to put aside prior personal knowledge and experience about the phenomenon. In addition, adequate time was spent with each participant, which was followed by intense engagement with the raw data. To support transferability, we provided rich and thorough descriptions of participants' experiences citing their verbatim statements. Dependability was ensured by a clear audit trail demonstrating how analytic decisions were made (Table 2). Confirmability was established by sharing the essential categories and themes with each participant. By the time all the interviews were completed, some of the participants had been discharged from the hospital. We conducted member checking by telephoning all the participants instead of returning our exhaustive description of the phenomenon to them. Although this was a slight modification of Colaizzi's method, all participants agreed that the identified themes captured the essence of their experiences of being a COVID-19 patient involved in family cluster transmission of the illness.

Patient and public involvement

Patients were involved in the design, conduct, and analysis phases of the research. Working with patients at the bedside enabled us to identify the research needs of this patient population and motivated us to undertake this research endeavor. While developing the interview guide, the research team received input from patients to ensure the appropriateness and relevance of the interview questions. As initial themes emerged, we reviewed the results with all patient participants to verify the findings and seek their additional feedback.

Results

Fourteen participants were recruited into the study. The sample consisted of seven males and seven females across an age range of 30 to 73. In the sample, four participants were the index case in the family. While the other ten participants contracted the disease from a close family member. The participants reported that two to five family members had been diagnosed with COVID-19 at the time of the study, with death toll reported in some participants' families (Table 3). Patients with COVID-19 involved in family cluster transmission in the study revealed emotional experiences that occurred during two distinct phases of their journey battling the infectious disease: the early outbreak phase and the later hospitalization phase. During each phase, three themes captured the essence of the participants' lived experiences.

Battling the unknown 'killer virus' early in the outbreak

In the early outbreak, participants described a variety of emotions combating this fatal new virus, characterized by feelings of stress, hopelessness, vulnerability, rejection, and guilt. The following three themes and the accompanying verbatim expressions illuminated participants' feelings of emotions.

Imbalances between individual wellbeing and family responsibilities

Following the outbreak in Wuhan in January, 2020, participants described that COVID-19 had expunged their normal existence. All participants in the study experienced significant imbalances of two basic life components between individual wellbeing and family responsibilities. Some participants went extra miles and made huge sacrifices to take care of their infected family members at the expense of neglecting their own illness. The sense of imbalance was captured in one participant's quotes:

"From January 27 to February 2, I only had about ten hours of sleep for the entire week since I had to get up around two o'clock every morning to line up in the hospital to get medicines for my daughter who was sick [with COVID-19] . . . Actually, I was just confirmed with the infection at that time. But I do not have time to worry about myself." (Participant 2)

Early in the COVID-19 outbreak, because of the extremely scarce healthcare resources available in Wuhan, many asymptomatic patients stayed at home under self-quarantine, which significantly increased the risk of person-to-person transmission of the infection within family clusters. To protect their family members, some participants desperately searched for a bed in a hospital so that they would not infect their loved ones at home. While reminiscing over his experience, one patient recalled:

"There were patients everywhere, but there were no [hospital] beds. I looked around all the hospitals in Wuhan and called so many friends, and I finally got a bed . . . I have a four-year old in my family. I am afraid of giving him the virus. So I ran away to protect my family. I haven't been able to see them for almost two months." (Participant 5)

Facing widespread prejudice and rejection

Having an unknown infectious disease made the participants feel being discriminated against by the public and even healthcare workers in the early stage of the outbreak. Many participants experienced rejection by fearful healthcare workers while seeking medical help. The sense of belittlement was best illustrated in the words of one participant:

"When we went to the hospital the first time in January, they [healthcare workers] really treated us [the patient and her husband] like bad guys, like mice, rotten mice. It felt like you [the patient and her husband] were so dirty, and you should not be near me. I cannot really tell you [the interviewer] the feeling." (Participant 3)

In a similar manner, another participant described vividly his experience of seeing a doctor:

"There was a table, and he [the doctor] sat far away. He turned his chair away from me. I could not move my chair getting near him because there was a table between us . . . He kept saying 'hey, hey, you stay away from me.' But I was just a patient who needed his help." (Participant 12)

People's desire to avoid infection and remain healthy resulted in obvious behaviors of social rejection. Having multiple family members infected added another layer of complexities to the social pain and distress, as described by the following participants:

"Three of us in the family were infected by the virus, and my mother-in-law died. People were just scared of us . . . My whole family have not contacted our relatives and friends out of Wuhan for more than one month. Everyone calls it 'Wuhan Virus.' We are 'Wuhan Virus' that can kill others. The prejudice is painful." (Participant 11)

"My daughter was infected after coming back to Wuhan for the Chinese Spring Festival. She said she would never come back to Wuhan again after her grandparents died [because of COVID-19] . . . She said there are too many painful memories in Wuhan. Everything about the family and the city [Wuhan] had changed to her." (Participant 2)

Heavy toll on the body and mind

COVID-19 took a heavy toll on the participants' body and mind. All the participants experienced unforgettable physical and psychological trauma in the early phase of the outbreak. The psychological impact came through clearly in the quotes of one patient as she described a deep sense of guilt for her father's death.

"On December 28, 2019, my family went to a friend child's tenth birthday party. At the party, there was another old couple who were relatives of our family. The couple died within 20 days after the gathering because of the virus . . . I was so scared when my father was tested positive. That was like a 'death sentence' because there was no hope to get him a hospital bed then. His condition deteriorated in a few days, and he died at home. I feel a lot of agony and pain in my heart. I cannot escape from the guilt. It feels like a monster living inside of me." (Participant 13)

Other patients described a high level of fear and anxiety for their own physical health, as recalled by one participant:

“When I went to the hospital that day, I coughed and had a lot of phlegm. I waited for hours to see a doctor. Finally, I had a checkup, CT [computerized tomography] scan, and the nurse took my blood. I did not get out of the hospital until 11 o'clock at night. There were no public transportation or Taxi services. Everything was shut down. I had to walk home, or maybe crawl back [home], or die on my way home as I was trembling and shivering.” (Participant 5)

While coping with the physical and psychological pain resulted from a deadly infectious disease, some participants experienced family loss and grief to an overwhelming degree since the early outbreak.

“Both of my parents died in January from the virus. I was not myself, thinking I might just go with them. I felt empty inside . . . My daughter became sick a week later, and she got the infection from me. I did not want to die without knowing what would happen to her.” (Participant 2)

Travelling on a voyage of uncertainty during hospitalization

After being hospitalized, participants had more time to think about their own health issues and reflect on their experiences. The feelings of uncertainty, sadness, fear of death, concerns about family, and hope for life prevailed in participants’ description of their experiences. Three themes were dominant across participants’ expression of emotions.

Living with uncertainty and sadness

Participants’ perception of uncertainty was related to the unknown and unpredictable nature of the illness. With the ever-increasing number of confirmed and suspected cases reported in the country, widespread social media coverage on the crisis, and a lack of effective standard treatment for the disease, participants expressed concerns about the long-term sequelae of the infection, possibilities of reoccurrence, and whether or not it would have any impact on their future family life. Some of the participants' quotes captured their emotions:

"People always talk about this virus. There are lots of rumors flying around. They are saying the virus will stay in your body forever just like the hepatitis B virus, and you will get sick again . . ." (Participate 12)

"I was originally planning to have a baby this year. I had a CT [computerized tomography] scan, and they [doctors] told me that the virus had done some damage to my body, and there might be some long-term effects on other parts of my body. I will have to postpone the plan to expand my family anytime soon." (Participant 8)

In viewing the heavy emotional toll on the general public after the SARS outbreak in China in 2003, the State Council of China opened up nationwide psychological counselling hotlines in early February, 2020. While staying on an isolation ward, all patients were able to use electronic devices and applications such as smartphones and WeChat to access free psychological counselling services anytime of the day. Nevertheless, some participants still felt living in a dark world of uncertainty and sadness:

"I am so frustrated. From the very beginning, I have had eight nucleic acid tests. My nucleic acid tests were negative, and then positive . . . over and over again. Nobody can explain to me why this is happening. I am constantly worried about what will happen next. But there is nothing I can do about it." (Participant 2)

“The city [Wuhan] has been locked down for more than one month. There were too many bad things that had happened during this time. I lost my daughter and my husband last month. My friends died. My relatives died. The pain and sadness are beyond recognition . . . I heard about the counselling hotline. But I do not think I need that. I just have to live with the pain.” (Participant 1)

Living with fear of death and concerns about family

The constant threat of death from the illness persisted in participants’ daily life. Having an unknown infection made participants feel extremely vulnerable to death. In addition, many participants in the study experienced physical challenges fighting the symptoms of the infection and/or unwanted side effects from medical treatment after being hospitalized. A patient recalled that:

“When I took Aluvia [Lopinavir/Ritonavir Tablets], I could not eat anything for three days because of nausea and vomiting. I have severe chronic enteritis . . . I knew that I would die if I did not eat. But I would also die if I did not take the medicine. It felt like I would die either way.” (Participant 14)

Some of the participants were transferred to the general isolation ward from COVID-ICUs. While receiving intensive care, the participants were exposed to daily death of other patients on the unit. Those were harrowing experiences to the participants inducing fear and sadness, as lamented by one participant:

“You don't understand the pain in my heart when I found out she [another ICU patient] died that night. She and I were admitted around the same time . . . I saw her body was taken away, thinking that the next time I would be the one they would be taking. I cried so badly for a few days. It was heart-wrenching." (Participant 6)

While admitted in the hospital, patients were able to access smartphones and wireless internet to communicate with their families. However, all participants felt great concerns about family life outside the isolation ward. The mandatory quarantine policy in a designated isolation center added another burden, as participants knew that their infected family members had been separated from the rest of the community. The participants' concerns were reflected in their accounts:

"All five of us in the family had been tested positive. We are in different hospitals and isolation centers . . . I know my family will be treated differently by other people. People in small cities used to envy people from Wuhan, but now Wuhan is notoriously famous all over the world." (Participant 7)

"My husband died in January. My son is at home by himself. He is fearless. He thinks that the virus will not get him. He has always been on my mind. I spoke to him on the phone yesterday. He said everything is fine. I have a feeling that he is hiding something from me. I just want to save him and myself from this crisis." (Participant 6)

Living with hope and gratitude

Despite the frightening and traumatizing experiences of living with a fatal virus infection, many participants exhibited enormous resilience toward the threat and fear of the illness. Some participants described that COVID-19 had promoted their personal growth and motivations for a better life in the future. For example:

“I have been staying in the hospital for over 40 days, and I have a lot time to think about the true meaning of life and existence. I live with hope as I want to survive this and spend the rest of my life with my family in good health. Nothing is more important than that.” (Participant 14)

Another participant described how living with COVID-19 had improved her family relationships:

“My husband and I were not too happy with each other before the outbreak. After I got sick, I told him that he should remarry someone else if I could not make it. My husband told me off, and he said ‘we started the family together. We will walk through this together. I am here for you, and you are there for me. We will be living happily after this’.” (Participant 11)

In addition to the positive state of seeking survival and a better family life, many participants felt that they were well taken care of by the hospital staff. By early March, 2020, the hospital where the study was conducted was primarily staffed by healthcare workers from across China. After going through the most acute phase of the infection, many participants felt a deep sense of security and gratitude for the medical treatment and care they had received:

“I feel that our country is great. So many patients need treatment. Our country has paid the medical bills for every patient . . . They [the government] sent you [healthcare workers] here to take care of us. From my heart, I feel indebted to the country and all the nurses and doctors.” (Participant 4)

While being admitted to an isolation ward, some patients perceived nurses as their family members, as the nurses helped them to eat, drink, and go to the bathroom. As one participant expressed:

“It is too hard for the nurses. They help us with everything since we do not have families with us . . . It must be so hot that their glasses [goggles] are sweaty. I cannot see their faces, but I remember all their names written on the back of their [personal protective] suits. They are like my daughters.” (Participant 3)

Another participant shared empathy toward nurses and doctors by arguing with another patient:

“Doctors and nurses are not our servants. If patients can move, we should do whatever we can by ourselves. There is no need to shout at doctors and nurses. I almost quarreled with another patient. I told him that ‘you [the other patient] are in a hospital. Eat and drink, doctors and nurses bring everything to your bed. You are sick; doctors and nurses take care of you day and night. I cannot stand the way you treat them.’” (Participant 5)

Living through the experiences of battling COVID-19, some participants extended empathy toward other patients and the community. As one participant recalled:

“It was very late that night when I was driven to the hospital [by ambulance]. They [the ambulance staff] told us they did not know who they should hand off us to, and they just left . . . There was another elderly man in the ambulance. We had to walk inside the hospital lobby by ourselves. He cannot really walk. So I walked slowly with him. If I had not helped him, he would have to crawl into the hospital by himself.” (Participant 9)

Another participant overheard the possibility of using convalescent plasma as a treatment for the illness and expressed his hope to save other patients’ lives by donating his plasma:

“I was very fit before I contracted the virus. I heard that some places are collecting plasma donations. If they still need the plasma, I can donate mine. I think I should be a good candidate for the donation. I am a soldier, and it is my nature to serve the country and the people. (Participant 10)

Discussion

Our findings suggest that patients' experiences and emotions evolved as they moved through different phases of the pandemic. Early in the outbreak, the transmission and mortality rates of COVID-19 were considerably high in Wuhan because of the unknown nature of the illness and the extremely strained local healthcare system. To protect their families, patient participants made great sacrifices by exposing themselves to risks for their family members or leaving families behind to prevent them from being infected. Such a high level of family obligation and altruism was based on the Chinese social merit of collectivism and doing what is best for the family at the expense of individual wellbeing.[20] Similarly, while under hospital care, some participants in the study lent helpful hands to other patients who were strangers. This finding is in line with Schwerdtle and colleagues' earlier study among African Ebola survivors who identified patients caring for each other as a source of resilience for self-preservation,[12] highlighting the prevalence of humanity and strength in crisis across different cultures and communities. Our finding further supports the possibilities of engaging patients with mild symptoms to participate in self-helping activities to restore their confidence in dealing with public health crisis.

Widespread prejudice and rejection from healthcare workers emerged as a major theme among participants describing their experiences combating COVID-19 in the early stage of the outbreak. The negative experiences might arise from the highly contagious nature of the illness and the heavy workload of healthcare workers. Moving into the hospitalization stage, participants did not express such negative feelings of rejection and neglect by healthcare workers anymore. A possible explanation for the change of participants' feelings might be attributed to the government's quick response efforts to strengthen the medical care capacity in Wuhan, which resulted in appropriate care provision to most of the patients. Our finding supports Liu and colleagues' emphasis on protecting healthcare workers from overwork and burnout during pandemic situations.[6] Of note, the literature also shows consistent evidence that survivors of Ebola and MERS experienced ostracism and rejection upon returning home after discharge from the hospital.[9 11] The stigma was perceived to arise from the public suspicion that survivors still had the virus in their bodies, a similar concern that was expressed by some of our participants. To facilitate easy reintegration of survivors of COVID-19 into the community, it is important to develop clear communication messages to the public that survivors are no longer contagious, and in effect require the utmost acceptance and care by members of the community.[21 22] In addition, healthcare workers could accompany survivors home after discharge to support their safe returning to the community.[11] It is equally important for the local government to make efforts to understand and address concerns of community members and engage them in plans to welcome survivors home.[23]

Following the outbreak in Wuhan in January, 2020, the number of patients admitted to the regional and provincial hospitals increased substantially. To alleviate the strain on the healthcare system and boost the manpower of the local hospitals, 25 633 healthcare workers from across China were deployed to Hubei province joining the fight against the outbreak as of February 14, 2020.[24] Furthermore, the government constructed new field hospitals and converted local stadiums to makeshift treatment centers, known as Fangcang Hospitals. By mid-February, 2020, any individuals with asymptomatic or mild infection were mandatorily quarantined at Fangcang Hospitals to reduce the person-to-person transmission in family clusters. If patients' conditions worsened, they were transferred to designated COVID-hospitals for further treatment. The decisions about interhospital transfers were made by the local government to ensure better coordination of care provision. Many patients in the study experienced separation from other infected family members because of the stratification admission policy based on the severity of clinical symptoms, which perpetuated their anxiety, despair, and fear during hospitalization. In addition, like survivors of past outbreaks,[11 12] witnessing the death of families, relatives, and other patients had been reported as a harrowing experience by participants in the present study. Although timely provision of mental health care was given the highest priority by the Chinese government since the early outbreak,[25] the psychological counseling services easily accessible to patients were not fully utilized owing to a lack of recognition of mental health issues by some of the participants. This finding highlights that patient education about the importance of mental health care cannot be overemphasized in a large-scale public health crisis like COVID-19. All these issues also suggest that psychological evaluations and brief supportive sessions should be routinely carried out virtually by mental health professionals to help those patients who are going through the infection and/or experiencing family loss and grief.[7] In addition, the essential personnel such as nurses who have the most frequent contact with patients should become more familiar with signs and symptoms of mental health issues and initiate early interventions by referring the patients to mental health professionals as needed.

In addition to the psychological counselling services, patients were encouraged to communicate with their families and friends using smartphones and WeChat for emotional support. Even with readily available ways of communication, many patient participants expressed great concerns about family life outside the isolation ward. Such findings were not surprising because of the fatal nature of the illness. While smartphones and WeChat facilitated easy communication between patients and family members, these communication channels also escalated the participants' stress levels. Throughout the outbreak, COVID-19 has been repeatedly described as a 'killer virus' on WeChat.[25] In addition, nobody could escape media coverage on the rapidly increasing number of new cases every day. Already following past outbreak, Matua and Wal argued that sensationalized media reporting and accounts created a sense of "inescapability of the Ebola experience" among patients and caregivers, which led to a widespread general panic beyond the geographic location of the actual epidemic.[26] Building on these findings, we encourage regular and accurate news updates from the local government and hospital officials about the outbreak. In addition, daily health status reports should be provided to both patients and family members. Nurses or other healthcare workers could telephone family members several times a week to update them and reassure them that their loves ones are cared for. In this way, family members are provided with accurate and reliable information about patient care. Caring for patients with COVID-19 should include both the patients and their families.

The feeling of uncertainty is a major theme in the participants' description of the essence of their experiences during hospitalization. The existing literature shows that uncertainty is a common theme for those living through an epidemic such as SARS and Ebola.[11 27] In the phenomenon of living with COVID-19, uncertainties of having a highly contagious disease, fear of death, and possible long-term consequences imposed a severe stressful mental state on all the participants. In order to reduce fear and uncertainty, public educational campaigns should be launched immediately after the outbreak focusing on the diagnosis, help-seeking behaviors, and prognosis of the illness. Furthermore, it is important that special clinics are set up to provide physical and psychological follow-ups on patient survivors. In addition, interprofessional and interorganizational collaborative efforts should be made to examine the physical and psychological sequelae of COVID-19, as well as investigate outcomes of existing intervention programs.[8]

The participants' negative experiences associated with emotional turmoil in the early phase of the outbreak contrasted with their positive experiences after being hospitalized. The difference in experiences throughout the participants' journey battling COVID-19 could have been explained by the improvement in healthcare service provisions and participants' transcendence from victimhood to empowerment. Uncertainty as a source of emotional distress can create opportunities for personal growth in crisis.[27] In the present study, the experience of living with uncertainty enabled participants to show appreciation for their lives and those of others. In particular, most of the participants expressed deep gratitude to healthcare workers during hospitalization. This finding differs from Schwerdtle and colleagues' report on Ebola survivors' experiences of abandonment by healthcare workers and healthcare facilities.[12] The difference in findings highlighted the importance of early government efforts and commitment to protect people's lives in catastrophic events. In addition, the positive feelings that participants held toward healthcare workers during hospitalization need to be situated and understood within the Chinese social and cultural contexts. Workplace violence against healthcare workers in China has been well documented.[28 29] A lack of communication between hospital staff and patients was identified as one of the root causes of workplace violence in China. The suboptimal working environments for Chinese healthcare workers are also related to the Chinese culture insisting on providing intimate personal care to patients by their family members or family-paid caregivers. In this cultural setting, healthcare workers are primarily charged with the responsibilities to treat the disease rather than the patient. Owing to the strict visiting restrictions imposed during the outbreak, family members and caregivers were not allowed to accompany the patients, and nurses took the major responsibility for basic care provision.[6] While staying on the isolation ward, patients in the present study witnessed healthcare workers' challenging working environments and their dedication to save the lives of others. Our finding strongly supports the positive effect of trusting and understanding relationships between patients and healthcare workers on combating public health crisis. Learning from the participants' experiences, nurses can develop a better understanding of the meaning of presence with and for their patients, the fundamental roles of nurses, and the ability of nurses to make significant changes on the lived world of patients.[27]

The limitations of the study must be acknowledged. First, our sample population consisted of patients with mild to moderate clinical symptoms, which limits the transferability of our findings to COVID-19 patient population at large. The descriptive phenomenological design determined the sample eligibility criteria. However, we recognize the need for further research that includes patients with different severities of the illness. Second, although we made every attempt throughout the study to bracket presuppositions, this alone might not have ensured validity of the findings. One presupposition that needed suspending was based on the fact that members of the research team also provided direct care to the participants. We noticed that participants often perceived us as clinical nurses and automatically kept thanking nurses during the interview. Therefore, we had to constantly remind the participants that we were there to learn from their experiences and what the experiences meant to them. Our reflexive notes also revealed that studying the experience of patients with COVID-19 during the crisis was an emotionally charged project. Nevertheless, our intention to reveal the experiences of those under our care made us determined to brave through the challenges.

Conclusion

The sudden emergence of COVID-19 has created devastating consequences around the world. In this study, we took a unique opportunity to explore the essence of the experiences of hospitalized patients with COVID-19 following family cluster transmission of the infection in Wuhan, the original epicenter of the pandemic. We were able to conduct the inquiry amidst the infectious outbreak because we were working alongside this patient population as their direct caregivers. Our findings intend to inform the development of specific intervention programs to prevent survivors from experiencing long-term physical and psychological consequences of the outbreak. Furthermore, this timely investigation of a new phenomenon can generate evidence-based information that might influence the development of guidelines on care provision for patients with COVID-19 in other countries whose outbreak occurred after China.

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Table 1 Interview guide

1. Can you tell me about your overall experiences after being infected?
2. How has your family role changed after being infected?
3. Reflecting on your personal experience, how has this changed your family responsibilities and/or relationships, and what has been the biggest challenge for you and your family?
4. Going forward, how do you think this experience would impact future life for you and your family?

Table 2 Selected examples of an audit trail

Theme	**Categories**	**Significant statements**	**Formulated meanings**
Imbalances between individual wellbeing and family responsibilities	Battling the unknown 'killer virus' early in the outbreak	"From January 27 to February 2, I only had about ten hours of sleep for the entire week since I had to get up around two o'clock every morning to line up in the hospital to get medicines for my daughter who was sick [with COVID-19] . . . Actually, I was just confirmed with the infection at that time. But I do not have time to worry about myself."	The participant felt being challenged to meet the healthcare needs of his own and his daughter.
Living with uncertainty and sadness	Travelling on a voyage of uncertainty during hospitalization	"I am so frustrated. From the very beginning, I have had eight nucleic acid tests. My nucleic acid tests were negative, and then positive . . . over and over again. Nobody can explain to me why this is happening. I am constantly worried about what will happen next. But there is nothing I can do about it."	The participant expressed a deep sense of frustration and uncertainty about his health condition.

Table 3 Demographics of the participants

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Living with COVID-19: A phenomenological study of hospitalized patients involved in family cluster transmission

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Living with COVID-19: A phenomenological study of hospitalized patients involved in family cluster transmission

Abstract

Objectives: To describe experiences of hospitalized patients with COVID-19 following family cluster transmission of the infection and the meaning of these experiences for them.

Design: A descriptive phenomenological design was used to construct themes depicting patients' experiences of living with COVID-19.

Setting: This study was conducted in a major teaching hospital in Wuhan, China in March, 2020.

Participants: Fourteen patients involved in family cluster transmission of COVID-19 were recruited into the study. The participants consisted of seven males and seven females. Data were collected through semi-structured, in-depth, face-to-face interviews. Interviews were transcribed verbatim and analyzed using Colaizzi's approach.

Results: Six themes emerged from data analysis during two distinct phases of patients going through COVID-19: the early outbreak phase and the later hospitalization phase. Early in the outbreak, patients experienced life imbalances between individual wellbeing and family responsibilities. While facing widespread prejudice and rejection, patients dealt with the heavy toll that the illness had left on their body and mind. After being hospitalized, patients described feelings of living with uncertainty, sadness, fear of death, and concerns about family, while simultaneously hoping for a better life after recovery.

Conclusions: Our findings suggest that living with COVID-19 is an emotionally and physically challenging experience for patient participants in the study. Psychological evaluations need to be routinely carried out with patients in a public health crisis. Interprofessional and

interorganizational collaborative efforts should be made to examine the physical and psychological sequelae of COVID-19, as well as investigate outcomes of existing intervention programs.

Strengths and limitations of this study

- Relatively few studies have been conducted to explore patient experiences of living with COVID-19.
- Working with patients at the bedside enabled us to identify the research needs of our patients and motivated us to undertake the inquiry into this vulnerable population.
- The major strength of this study is the phenomenological approach used to describe hospitalized patients' thoughts, health situations, feelings, and behaviors amidst the infectious outbreak.
- Our sample population consisted of patients with mild to moderate clinical symptoms, which limits the transferability of our findings to COVID-19 patient population at large.

Introduction

In December, 2019, a novel coronavirus disease later known as COVID-19 emerged in Wuhan, the capital city of Hubei province in China. Within one month, the deadly viral disease spread from a single city to the entire country.[1] Because of its strong human-to-human transmission ability, COVID-19 soon became a global public health concern.[2] On March 11, 2020, the World Health Organization officially declared COVID-19 a global pandemic.[3] In the meantime, global collaborative research efforts have been made to share real-time data combating the pandemic. The pertinent research on the viral disease concerning its clinical and epidemiological features and possible transmission routes is ever-expanding.[4 5] Even the lived experiences of frontline healthcare workers caring for patients with COVID-19 are growing rapidly.[6 7] However, relatively few studies have been conducted to explore the real-life experiences of those affected by the illness, especially when they are admitted to the hospital.

The earliest report on patients' experiences of living with COVID-19 was documented by Sahoo et al. in October, 2020. The case descriptions of three patients revealed highly distressing mental health issues that patients experienced on hospital isolation units.[8] Within the available literature on patients' lived experiences, Shaban and colleagues' hermeneutical inquiry of 11 patients with COVID-19 provides a rich insight into how patients delt with their emotions in the context of hospital isolation. The researchers suggested changes to physical environments and development of care models to minimize the negative consequences of isolation in healthcare settings.[9] Most recently, the body of work has shifted from patients to survivors primarily focusing on their health-related beliefs,[10] along with their persistent physical and psychological issues during and after COVID-19.[11 12] In light of the resurgence of the pandemic in many countries around the world, there is an increased need to glean more insight into the lifeworld of those vulnerable patients in order to inform evidence-based clinical practice.[13]

Early in the outbreak of the pandemic, many case studies reported in China have demonstrated consistent evidence on rapid transmission of COVID-19 in the form of family clusters.[4 5] Consequently, extraordinary public health measures and education campaigns have been implemented to reduce further spread of the virus within China and elsewhere.[2] While there have been studies on the biomedical aspects of the illness and the experiences of healthcare workers and survivors, relatively few studies have been done to explore patient experiences in the mid of COVID-19. A better understanding of patients' lived experiences might help to inform local and national efforts to strengthen service provision for patients and their families during and after the outbreak. Healthcare workers will also benefit from the perspectives of the recipients of their care in preparation for the current resurgence of COVID-19 and future pandemics.[14] Given that COVID-19 is transmitted quickly within family clusters, we endeavored to explore the experiences of patients originated from family cluster contexts to clarify the individual and family impact of the outbreak. The central research question guiding the study was: "What is the experience of living with COVID-19 following family cluster transmission of the illness?"

Methods

Design

Descriptive phenomenology was the research design selected for the study. Husserl's philosophical underpinnings are foundational to descriptive phenomenology.[15] Husserl's approach has been adopted to shed new light on nurses' experiential accounts in caring for patients with COVID-19.[6 16] For Husserl, the aim of phenomenology is to arrive at an essential understanding of human consciousness through describing features common to all people who have the experience.[17] Descriptive phenomenology is most suitable to make an inquiry into universal aspects of a phenomenon that have never been conceptualized in prior research.[18] Living with COVID-19 is a new phenomenon, and existing literature on the outbreak does not readily inform us about the inherent complexities and intricacies of patients' emotional responses to this unprecedented crisis.

Inherent in descriptive phenomenology is the principle of bracketing by holding in abeyance preconceived beliefs and opinions about the phenomenon under study.[15] Through bracketing, the essence of the phenomenon emerges from the perspective of those experiencing it. Bracketing for this study was accomplished through reflexive journaling. Throughout the study, reflexive notes regarding preconceptions and presuppositions, experiences of the research team caring for patients with COVID-19, together with thoughts after interviews were recorded and discussed among members of the research team during our daily WeChat video conferences. Because of the dual role of the members of the research team as nurses and researchers, we intended to meet the phenomenon as rigorous and unbiased as possible. Descriptive phenomenology offered us the methodological tools to refrain from our judgement and focus on describing the lived experience as opposed to interpreting or explaining it. Furthermore, reflexive notes were revisited prior to each interview and during data analysis to ensure the interviewer-imposed assumptions did not take precedent over the participants' described experiences.

Setting and participants

The study was conducted in a large teaching hospital in Wuhan, China. Our research team primarily consisted of nurses who were deployed to Wuhan from another teaching hospital in Hunan province to work intensively with this patient population. Following our deployment to Wuhan, members of the research team were assigned to work in a 55-bed occupancy general isolation ward where patients were admitted with mild to moderate COVID-19 symptoms for isolation or transferred from intensive care units (ICUs) waiting for discharge. All patients on the general isolation ward were able to perform activities of daily living independently or with minimal assistance. The patients were free to move around the public areas on the isolation ward such as hallways and tea rooms while wearing face masks and keeping physical distance. While working with patients closely on the isolation ward, members of the research team were constantly intrigued by the patients' needs to share their stories with frontline healthcare workers, particularly nurses. Initially, we were concerned about our ability to meet the phenomenon completely unprejudiced. But the merits of conducting this research outweighed any potential harm to scientific rigor. Finally, we decided to take this unique opportunity and apply rigorous research methods to investigate the lived experiences of those patients that we cared for.

To concentrate on our clinical responsibilities and meet the phenomenon as free as possible, we assigned specific nursing staff members to recruit participants and conduct interviews. The sample criteria required that the patient was involved in family cluster transmission; was willing and able to articulate his or her experience; and had stable physical conditions (e.g. Oxygenation Index ≧300mmHg). In addition, healthcare providers' opinions were sought to determine the appropriateness of patients' participation in the study. Participants were recruited using a combination of convenience, snowball, and purposive sampling strategies. Our first three participants responded to the research flyers posted in the public areas of the general isolation ward. The rest of the participants were recruited through snowball sampling. To maximize the sample variations, we purposively took into consideration of the index case in the family, the number of patients in each family cluster, and the number of deaths in the family. In addition, we purposively recruited all participants from different family clusters attempting to generate rich perspectives because of the exploratory nature of the study. Patients' experiences from the same family clusters are distinctive ones with an additional layer of complexities and dynamics, warranting a separate study of this potentially vast population.

Ethics

Approval to conduct this study was given by the Institutional Review Board from Tongji Hospital where the study was conducted (stamped and approved) and The Third Xiangya Hospital of Central South University where the researchers were deployed from (No: 2020-S333). All participants were informed of the voluntary nature of the study, and they were allowed to withdraw from the study at any time without any consequences to the care provided to them. Because of the sensitive nature of the research topic, participants might be referred to a mental health counsellor in the hospital if they showed strong emotional responses to the interview questions. The referral would only be made with individual participant's permission. Furthermore, the interviewer showed participants empathy throughout the interviews and constantly bracketed out her personal feelings. Written consent was obtained from all participants before the start of the interview. Confidentiality was ensured by assigning a unique participant number to replace participants' names on the transcripts. All electronic data were kept in password-protected files on computers, which were in a secure place and only accessed by members of the research team. The raw data (e.g. reflexive notes, audio-recordings) were stored separately in a locked facility.

Data collection

Semi-structured, in-depth, face-to-face interviews were conducted between March 1 and March 25, 2020. All interviews were conducted in a private, quiet conference room on the isolation ward to ensure privacy, participant comfort, and to promote open sharing of experiences. During the entire interview, both the interviewer and the interviewee wore new face masks and sat apart from each other with six feet physical distance. Each interview lasted between 40 and 60 minutes, and it was audio-recorded. Demographic information about each participant was obtained at the start of the interview. Interviews began with a broad open-ended question asking, "What is it like to be a patient living with COVID-19?" Prompts from the interview guide were used to encourage participants to elaborate on their experiences (Table 1). Having daily interactions with patients on the unit helped the research team to develop interview questions that were most pertinent to patients' experiences living with COVID-19.

To separate our researcher and caregiver roles, we recruited a Master-degree prepared nursing staff member who was not directly affiliated with the study to conduct all interviews. Prior to the conduct of patient interviews, the nursing staff organized practice interviews with a qualitative researcher on the research team to validate appropriate interview skills and bracketing were implemented throughout the investigation. The audio-recording was transcribed verbatim by two members of the research team within 24 hours, and the interviewer's reflexive notes were discussed among members of the research team. The interviews and original transcripts were originally recorded in Chinese. All quotations were translated into English language by the first author (female) and back translated into Chinese language by the co-first author (female) to assess semantic equivalence between the original and back translated versions of the transcripts.[19] Data collection continued until data saturation had been achieved as evidenced by redundant information kept emerging.

Data analysis

All audio and written data were imported into NVivo 12 (QRS International) to assist with data management and categorization. The analysis based on Colaizzi's method included the following seven steps: 1) Reading all the transcripts three to five times to gain an understanding of meanings conveyed; 2) Reviewing each description and extracting significant statements; 3) Formulating meanings for these significant statements; 4) Categorizing the formulated meanings into clusters of themes; 5) Integrating the findings into an exhaustive description of the phenomenon; 6) Returning the exhaustive description to participants for validation of feelings, and 7) Incorporating any relevant new data into final description of the essence of the phenomenon.[20] In the present study, 150 significant statements were extracted from the transcribed interviews. These significant statements were then transformed into 42 formulated meaning units. These formulated meaning units were later grouped into two main categories with six distinct themes discussed in the findings. Initial data coding was completed by two members of the research team. Nevertheless, there were ongoing discussions among all research team members about the analysis of the data, and the research team reached an agreement on final findings presented in this paper. Throughout the paper, we followed the Consolidated Criteria for Reporting Qualitative Research (COREQ).[21]

Trustworthiness

To enhance trustworthiness of the study, we followed Lincoln and Guba's definitions for the establishment of rigor in qualitative research.[22] To ensure credibility, bracketing was implemented throughout the research process to put aside prior personal knowledge and experience about the phenomenon. In addition, adequate time was spent with each participant, which was followed by intense engagement with the raw data. To support transferability, we provided rich and thorough descriptions of participants' experiences citing their verbatim statements. Dependability was ensured by a clear audit trail demonstrating how analytic decisions were made (Table 2). Confirmability was established by sharing the essential categories and themes with each participant. By the time all the interviews were completed, some of the participants had been discharged from the hospital. We conducted member checking by telephoning all the participants instead of returning our exhaustive description of the phenomenon to them. Although this was a slight modification of Colaizzi's method, all participants agreed that the identified themes captured the essence of their experiences of being a COVID-19 patient involved in family cluster transmission of the illness.

Patient and public involvement

Patients were involved in the design, conduct, and analysis phases of the research. Working with patients at the bedside enabled us to identify the research needs of this patient population and motivated us to undertake this research endeavor. While developing the interview guide, the research team received input from patients to ensure the appropriateness and relevance of the interview questions. As initial themes emerged, we reviewed the results with all patient participants to verify the findings and seek their additional feedback.

Results

Fourteen participants were recruited into the study. The sample consisted of seven males and seven females across an age range of 30 to 73. In the sample, four participants were the index case in the family. While the other ten participants contracted the disease from a close family member. The participants reported that two to five family members had been diagnosed with COVID-19 at the time of the study, with death toll reported in some participants' families (Table 3). Patients with COVID-19 involved in family cluster transmission in the study revealed emotional experiences that occurred during two distinct phases of their journey battling the infectious disease: the early outbreak phase and the later hospitalization phase. During each phase, three themes captured the essence of the participants' lived experiences.

Battling the unknown 'killer virus' early in the outbreak

In the early outbreak, participants described a variety of emotions combating this fatal new virus, characterized by feelings of stress, hopelessness, vulnerability, rejection, and guilt. The following three themes and the accompanying verbatim expressions illuminated participants' feelings of emotions.

Imbalances between individual wellbeing and family responsibilities

Following the outbreak in Wuhan in January, 2020, participants described that COVID-19 had expunged their normal existence. All participants in the study experienced significant imbalances of two basic life components between individual wellbeing and family responsibilities. Some participants went extra miles and made huge sacrifices to take care of their infected family members at the expense of neglecting their own illness. The sense of imbalance was captured in one participant's quotes:

"From January 27 to February 2, I only had about ten hours of sleep for the entire week since I had to get up around two o'clock every morning to line up in the hospital to get medicines for my daughter who was sick [with COVID-19] . . . Actually, I was just confirmed with the infection at that time. But I do not have time to worry about myself." (Participant 2)

Early in the COVID-19 outbreak, because of the extremely scarce healthcare resources available in Wuhan, many asymptomatic patients stayed at home under self-isolation, which significantly increased the risk of person-to-person transmission of the infection within family clusters. To protect their family members, some participants desperately searched for a bed in a hospital so that they would not infect their loved ones at home. While reminiscing over his experience, one patient recalled:

“There were patients everywhere, but there were no [hospital] beds. I looked around all the hospitals in Wuhan and called so many friends, and I finally got a [hospital] bed . . . I have a four-year old in my family. I am afraid of giving him the virus. So I ran away to protect my family. I haven’t been able to see them for almost two months.” (Participant 5)

Facing widespread prejudice and rejection

Having an unknown infectious disease made the participants feel being discriminated against by the public and even healthcare workers in the early stage of the outbreak. Many participants experienced rejection by fearful healthcare workers while seeking medical help. The sense of belittlement was best illustrated in the words of one participant:

“When we went to the hospital the first time in January, they [healthcare workers] really treated us [the patient and her husband] like bad guys, like mice, rotten mice. It felt like you [the patient and her husband] were so dirty, and you should not be near me. I cannot really tell you [the interviewer] the feeling.” (Participant 3)

People’s desire to avoid infection and remain healthy resulted in obvious behaviors of social rejection. Having multiple family members infected added another layer of complexities to the social pain and distress, as described by the following participants:

“Three of us in the family were infected by the virus, and my mother-in-law died. People were just scared of us . . . My whole family have not contacted our relatives and friends out of Wuhan for more than one month. Everyone calls it ‘Wuhan Virus.’ We are ‘Wuhan Virus’ that can kill others. The prejudice is painful.” (Participant 11)

“My daughter was infected after coming back to Wuhan for the Chinese Spring Festival. She said she would never come back to Wuhan again after her grandparents died [because of COVID-19] . . . She said there are too many painful memories in Wuhan. Everything about the family and the city [Wuhan] had changed to her.” (Participant 2)

Heavy toll on the body and mind

COVID-19 took a heavy toll on the participants’ body and mind. All the participants experienced unforgettable physical and psychological trauma in the early phase of the outbreak. The psychological impact came through clearly in the quotes of one patient as she described a deep sense of guilt for her father’s death.

“On December 28, 2019, my family went to a friend child's tenth birthday party. At the party, there was another old couple who were relatives of our family. The couple died within 20 days after the gathering because of the virus . . . I was so scared when my father was tested positive. That was like a ‘death sentence’ because there was no hope to get him a hospital bed then. His condition deteriorated in a few days, and he died at home. I feel a lot of agony and pain in my heart. I cannot escape from the guilt. It feels like a monster living inside of me.” (Participant 13)

Other patients described a high level of fear and anxiety for their own physical health, as recalled by one participant:

“When I went to the hospital that day, I coughed and had a lot of phlegm. I waited for hours to see a doctor. Finally, I had a checkup, CT [computerized tomography] scan, and the nurse took my blood. I did not get out of the hospital until 11 o'clock at night. There were no public transportation or Taxi services. Everything was shut down. I had to walk home, or maybe crawl back [home], or die on my way home as I was trembling and shivering." (Participant 5)

While coping with the physical and psychological pain resulted from a deadly infectious disease, some participants experienced family loss and grief to an overwhelming degree since the early outbreak.

"Both of my parents died in January from the virus. I was not myself, thinking I might just go with them. I felt empty inside . . . My daughter became sick a week later, and she got the infection from me. I did not want to die without knowing what would happen to her." (Participant 2)

Travelling on a voyage of uncertainty during hospitalization

After being hospitalized, participants had more time to think about their own health issues and reflect on their experiences. The feelings of uncertainty, sadness, fear of death, concerns about family, and hope for life prevailed in participants' description of their experiences. Three themes were dominant across participants' expression of emotions.

Living with uncertainty and sadness

Participants' perception of uncertainty was related to the unknown and unpredictable nature of the illness. With the ever-increasing number of confirmed and suspected cases reported in the country, widespread social media coverage on the crisis, and a lack of effective standard treatment for the disease, participants expressed concerns about the long-term sequelae of the infection, possibilities of reoccurrence, and whether or not it would have any impact on their future family life. Some of the participants' quotes captured their emotions:

"People always talk about this virus. There are lots of rumors flying around. They are saying the virus will stay in your body forever just like the hepatitis B virus, and you will get sick again . . ." (Participate 12)

"I was originally planning to have a baby this year. I had a CT [computerized tomography] scan, and they [doctors] told me that the virus had done some damage to my body, and there might be some long-term effects on other parts of my body. I will have to postpone the plan to expand my family anytime soon." (Participant 8)

In viewing the heavy emotional toll on the general public after the SARS outbreak in China in 2003, the State Council of China opened up nationwide psychological counselling hotlines in early February, 2020. While staying on an isolation ward, all patients were able to use electronic devices and applications such as smartphones and WeChat to access free psychological counselling services anytime of the day. Nevertheless, some participants still felt living in a dark world of uncertainty and sadness:

"I am so frustrated. From the very beginning, I have had eight nucleic acid tests. My nucleic acid tests were negative, and then positive . . . over and over again. Nobody can explain to me why this is happening. I am constantly worried about what will happen next. But there is nothing I can do about it." (Participant 2)

"The city [Wuhan] has been locked down for more than one month. There were too many bad things that had happened during this time. I lost my daughter and my husband last month. My friends died. My relatives died. The pain and sadness are beyond recognition . . . I heard about the counselling hotline. But I do not think I need that. I just have to live with the pain." (Participant 1)

Living with fear of death and concerns about family

The constant threat of death from the illness persisted in participants' daily life. Having an unknown infection made participants feel extremely vulnerable to death. In addition, many participants in the study experienced physical challenges fighting the symptoms of the infection and/or unwanted side effects from medical treatment after being hospitalized. A patient recalled that:

> "When I took Aluvia [Lopinavir/Ritonavir Tablets], I could not eat anything for three days because of nausea and vomiting. I have severe chronic enteritis . . . I knew that I would die if I did not eat. But I would also die if I did not take the medicine. It felt like I would die either way." (Participant 14)

Some of the participants were transferred to the general isolation ward from COVID-ICUs. While receiving intensive care, the participants were exposed to daily death of other patients on the unit. Those were harrowing experiences to the participants inducing fear and sadness, as lamented by one participant:

> "You don't understand the pain in my heart when I found out she [another ICU patient] died that night. She and I were admitted around the same time . . . I saw her body was taken away, thinking that the next time I would be the one they would be taking. I cried so badly for a few days. It was heart-wrenching." (Participant 6)

While admitted in the hospital, patients were able to access smartphones and wireless internet to communicate with their families. However, all participants felt great concerns about family life outside the isolation ward. The mandatory quarantine policy in a designated isolation center added another burden, as participants knew that their infected family members had been separated from the rest of the community. The participants' concerns were reflected in their accounts:

"All five of us in the family had been tested positive. We are in different hospitals and isolation centers . . . I know my family will be treated differently by other people. People in small cities used to envy people from Wuhan, but now Wuhan is notoriously famous all over the world." (Participant 7)

"My husband died in January. My son is at home by himself. He is fearless. He thinks that the virus will not get him. He has always been on my mind. I spoke to him on the phone yesterday. He said everything is fine. I have a feeling that he is hiding something from me. I just want to save him and myself from this crisis." (Participant 6)

Living with hope and gratitude

Despite the frightening and traumatizing experiences of living with a fatal virus infection, many participants exhibited enormous resilience toward the threat and fear of the illness. Some participants described that COVID-19 had promoted their personal growth and motivations for a better life in the future. For example:

"I have been staying in the hospital for over 40 days, and I have a lot of time to think about the true meaning of life and existence. I live with hope as I want to survive this and spend the rest of my life with my family in good health. Nothing is more important than that." (Participant 14)

Another participant described how living with COVID-19 had improved her family relationships:

"My husband and I were not too happy with each other before the outbreak. After I got sick, I told him that he should remarry someone else if I could not make it. My husband told me off, and he said ‘we started the family together. We will walk through this together. I am here for you, and you are there for me. We will be living happily after this’.” (Participant 11)

In addition to the positive state of seeking survival and a better family life, many participants felt that they were well taken care of by the hospital staff. By early March, 2020, the hospital where the study was conducted was primarily staffed by healthcare workers from across China. After going through the most acute phase of the infection, many participants felt a deep sense of security and gratitude for the medical treatment and care they had received. While being admitted to an isolation ward, some patients perceived nurses as their family members, as the nurses helped them to eat, drink, and go to the bathroom. As one participant expressed:

“It is too hard for the nurses. They help us with everything since we do not have families with us . . . It must be so hot that their glasses [goggles] are sweaty. I cannot see their faces, but I remember all their names written on the back of their [personal protective] suits. They are like my daughters.” (Participant 3)

Living through the experiences of battling COVID-19, some participants extended empathy toward other patients and the community. As one participant recalled:

“It was very late that night when I was driven to the hospital [by ambulance]. They [the ambulance staff] told us they did not know who they should hand off us to, and they just left . . . There was another elderly man in the ambulance. We had to walk inside the hospital lobby by ourselves. He cannot really walk. So I walked slowly with him. If I had not helped him, he would have to crawl into the hospital by himself.” (Participant 9)

Another participant overheard the possibility of using convalescent plasma as a treatment for the illness and expressed his hope to save other patients’ lives by donating his plasma:

"I was very fit before I contracted the virus. I heard that some places are collecting plasma donations. If they still need the plasma, I can donate mine. I think I should be a good candidate for the donation. I am a soldier, and it is my nature to serve the country and the people. (Participant 10)

Discussion

Our findings suggest that patients' experiences and emotions evolved as they moved through different phases of the pandemic. Early in the outbreak, the transmission and mortality rates of COVID-19 were considerably high in Wuhan because of the unknown nature of the illness and the extremely strained local healthcare system. To protect their families, patient participants made great sacrifices by exposing themselves to risks for their family members or leaving families behind to prevent them from being infected. Such a high level of family obligation and altruism was based on the Chinese social merit of collectivism and doing what is best for the family at the expense of individual wellbeing.[23] Similarly, while under hospital care, some participants in the study lent helpful hands to other patients who were strangers. This finding is in line with earlier study among African Ebola survivors who identified patients caring for each other as a source of resilience for self-preservation, highlighting the prevalence of humanity and strength in crisis across different cultures and communities.[14] Our findings further support Ladds and colleagues' call to establish online peer support groups during and after COVID-19 to share patients' experiences and knowledge about the illness.[12]

Participants in our study conveyed both negative emotions of feeling rejected in the early stage of the outbreak and positive experiences of receiving quality care during hospitalization. A possible explanation for the change of participants' feelings might be attributed to the government's quick response efforts to strengthen the medical care capacity in Wuhan, which resulted in appropriate care provision to most of the patients. Our finding supports Liu and colleagues' emphasis on protecting healthcare workers from overwork and burnout during pandemic situations.[7] Of note, the available literature also shows consistent evidence that survivors of COVID-19 experienced rejection and stigmatization after recovering from the illness .[10 11] The stigma was perceived to arise from the public suspicion that survivors still had the virus in their bodies, a similar concern that was expressed by some of our participants. To facilitate easy reintegration of survivors of COVID-19 into the community, it is important to develop clear communication messages to the public that survivors are no longer contagious, and in effect require the utmost acceptance and care by members of the community.[24] In addition, healthcare workers could accompany survivors home after discharge to support their safe returning to the community.[25] It is equally important to create a positive environment in the community where the COVID-19 disease and its effects can be discussed openly and effectively.[11]

Following the outbreak in Wuhan in January, 2020, the number of patients admitted to the regional and provincial hospitals increased substantially. To alleviate the strain on the healthcare system and boost the manpower of the local hospitals, 25 633 healthcare workers from across China were deployed to Hubei province joining the fight against the outbreak as of February 14, 2020.[26] Furthermore, the government constructed new field hospitals and converted local stadiums to makeshift treatment centers, known as Fangcang Hospitals. By mid-February, 2020, any individuals with asymptomatic or mild infection were mandatorily isolated at Fangcang Hospitals to reduce the person-to-person transmission in family clusters. If patients' conditions worsened, they were transferred to designated COVID-hospitals for further treatment. The decisions about interhospital transfers were made by the local government to ensure better coordination of care provision. Many patients in the study experienced separation from other infected family members because of the stratification admission policy based on the severity of clinical symptoms, which perpetuated their anxiety, despair, and fear during hospitalization. In addition, witnessing the death of families, relatives, and other patients had been reported as a harrowing experience by participants in the present study, affirming survivors' experience of feeling being trapped between life and death while living with COVID-19.[11] Although timely provision of mental health care was given the highest priority by the Chinese government since the early outbreak,[27] the psychological counseling services easily accessible to patients were not fully utilized owing to a lack of recognition of mental health issues by some of the participants. This finding highlights that patient education about the importance of mental health care cannot be overemphasized in a large-scale public health crisis like COVID-19. All these issues also suggest that psychological evaluations and brief supportive sessions should be routinely carried out virtually by mental health professionals to help those patients who are going through the infection and/or experiencing family loss and grief.[8] In addition, the essential personnel such as nurses who have the most frequent contact with patients should become more familiar with signs and symptoms of mental health issues and initiate early interventions by referring the patients to mental health professionals as needed.

In addition to the psychological counselling services, patients were encouraged to communicate with their families and friends using smartphones and WeChat for emotional support. Even with readily available ways of communication, many patient participants expressed great concerns about family life outside the isolation ward. Such findings were not surprising because of the fatal nature of the illness. While smartphones and WeChat facilitated easy communication between patients and family members, these communication channels also escalated the participants' stress levels. Throughout the outbreak, COVID-19 has been repeatedly described as a 'killer virus' on WeChat.[27] In addition, nobody could escape media coverage on the rapidly increasing number of new cases every day. Already reported in other studies, patients with COVID-19 criticized sensationalized social media platforms for creating coronavirus "infodemic" and exacerbated the anxiety level of the general public.[9 11] Building on these findings, we encourage regular and accurate news updates from the local government and hospital officials about the outbreak. Nurses or other healthcare workers could telephone family members several times a week to update them and reassure them that their loves ones are cared for. In the meantime, we support the continued use of smartphones by patients in isolation to communicate with their family and friends, and to establish a sense of connectedness with the world outside.

The feeling of uncertainty is a major theme in the participants' description of the essence of their experiences during hospitalization. The existing literature shows that uncertainty is a common theme for those living throughCOVID-19.[10 12] In the phenomenon of living with COVID-19, uncertainties of having a highly contagious disease, fear of death, and possible long-term consequences imposed a severe stressful mental state on all the participants. In order to reduce fear and uncertainty, public educational campaigns should be launched immediately after the outbreak focusing on the diagnosis, help-seeking behaviors, and prognosis of the illness. In addition, interprofessional and interorganizational collaborative efforts should be made to examine the physical and psychological sequelae of COVID-19, as well as investigate outcomes of existing intervention programs.[28]

The participants' negative experiences associated with emotional turmoil in the early phase of the outbreak contrasted with their positive experiences after being hospitalized. The difference in experiences throughout the participants' journey battling COVID-19 could have been explained by the improvement in healthcare service provisions and participants' transcendence from victimhood to empowerment. Uncertainty as a source of emotional distress can create opportunities for personal growth in crisis.[29] In the present study, the experience of living with uncertainty enabled participants to show appreciation for their lives and those of others. In particular, most of the participants expressed deep gratitude to healthcare workers during hospitalization. This finding differs from Ebola survivors' experiences of abandonment by healthcare workers and healthcare facilities in West Africa.[14] The healthcare system infrastructure and personnel knowledge and skills in different countries could have led to the difference in findings. Our findings highlighted the importance of early government efforts and commitment to protect people's lives in catastrophic events. In addition, the positive feelings that participants held toward healthcare workers during hospitalization need to be situated and understood within the Chinese social and cultural contexts. Workplace violence against healthcare workers in China has been well documented.[30 31] In Chinese culture, healthcare workers are primarily charged with the responsibilities to treat the disease rather than the patient. Owing to the strict visiting restrictions imposed during the outbreak, family members and caregivers were not allowed to accompany the patients, and nurses took the major responsibility for basic care provision.[7] While staying on the isolation ward, patients in the present study witnessed healthcare workers' challenging working environments and their dedication to save the lives of others. Our finding strongly supports the positive effect of trusting and understanding relationships between patients and healthcare workers on combating public health crisis. Learning from the participants' experiences, nurses can develop a better understanding of the meaning of presence with and for their patients, the fundamental roles of nurses, and the ability of nurses to make significant changes on the lived world of patients.[29]

The dual role of the members of the research team as researchers and caregivers during this inquiry is worth mentioning. Being nurses afforded us upmost closeness to the patients and provided us with the opportunity to share the knowledge discovery process with those under our direct care. Although the research team endeavored to separate out our clinical and research roles by assigning nurses outside of the research team to recruit participants and conduct interviews, patients might have felt more connected to nursing research activities and answered with more emphasis on nursing care than usual because of our dual role positions. To ensure the voluntary nature of participation and protecting patient wellbeing, we adopted the ethical practice of "responsible advocacy" by seeking opinions from healthcare providers to determine an individual's appropriateness of participation.[32] Beyond the formal ethical guidelines, we defined our guiding ethics of practices through extensive professional nursing experience.

The limitations of the study must be acknowledged. First, our sample population consisted of patients with mild to moderate clinical symptoms, which limits the transferability of our findings to COVID-19 patient population at large. The descriptive phenomenological design determined the sample eligibility criteria. However, we recognize the need for further research that includes patients with different severities of the illness. Second, although we made every attempt throughout the study to bracket presuppositions, this alone might not have ensured validity of the findings. One presupposition that needed suspending was based on the fact that members of the research team also provided direct care to the participants. We noticed that participants often perceived us as clinical nurses and automatically kept thanking nurses during the interview. Therefore, we had to constantly remind the participants that we were there to learn from their experiences and what the experiences meant to them. Our reflexive notes also revealed that studying the experience of patients with COVID-19 during the crisis was an emotionally charged project. Nevertheless, our intention to reveal the experiences of those under our care made us determined to brave through the challenges.

Conclusion

The sudden emergence of COVID-19 has created devastating consequences around the world. In this study, we took a unique opportunity to explore the essence of the experiences of hospitalized patients with COVID-19 following family cluster transmission of the infection in Wuhan, the original epicenter of the pandemic. We were able to conduct the inquiry amidst the infectious outbreak because we were working alongside this patient population as their direct caregivers. Our findings intend to inform the development of specific intervention programs to prevent survivors from experiencing long-term physical and psychological consequences of the outbreak. Furthermore, this timely investigation of a new phenomenon can generate evidence-based information that might influence the development of guidelines on care provision for patients with COVID-19 in other countries whose outbreak occurred after China.

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Table 1 Interview guide

1. Can you tell me about your overall experiences after being infected?
2. How has your family role changed after being infected?
3. Reflecting on your personal experience, how has this changed your family responsibilities and/or relationships, and what has been the biggest challenge for you and your family?
4. Going forward, how do you think this experience would impact future life for you and your family?

Table 2 Selected examples of an audit trail

Theme	**Categories**	**Significant statements**	**Formulated meanings**
Imbalances between individual wellbeing and family responsibilities	Battling the unknown 'killer virus' early in the outbreak	"From January 27 to February 2, I only had about ten hours of sleep for the entire week since I had to get up around two o'clock every morning to line up in the hospital to get medicines for my daughter who was sick [with COVID-19] . . . Actually, I was just confirmed with the infection at that time. But I do not have time to worry about myself."	The participant felt being challenged to meet the healthcare needs of his own and his daughter.
Living with uncertainty and sadness	Travelling on a voyage of uncertainty during hospitalization	"I am so frustrated. From the very beginning, I have had eight nucleic acid tests. My nucleic acid tests were negative, and then positive . . . over and over again. Nobody can explain to me why this is happening. I am constantly worried about what will happen next. But there is nothing I can do about it."	The participant expressed a deep sense of frustration and uncertainty about his health condition.

Table 3 Demographics of the participants

	Gender	Age (years)	Index case †	Number of patients in the family cluster	Death in the family cluster from COVID-19
Participant 1	Female	70-75	The eldest daughter	4	The eldest daughter and husband
Participant 2	Male	45-50	Father	4	Mother and father
Participant 3	Female	50-55	Husband	2	No one
Participant 4	Female	50-55	Patient self	3	No one
Participant 5	Male	70-75	Patient self	2	No one
Participant 6	Female	55-60	Husband	2	Husband
Participant 7	Female	50-55	Patient self	5	No one
Participant 8	Male	30-35	Father-in-law	2	No one
Participant 9	Male	65-70	Patient self	2	No one
Participant 10	Male	70-75	Wife	2	Wife
Participant 11	Female	40-45	Mother-in-law	3	Mother-in-law
Participant 12	Male	60-65	Wife	2	Wife
Participant 13	Female	35-40	Father	3	Father
Participant 14	Male	55-60	Mother	4	Mother

† Index case was the first case tested positive in the family cluster.

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Reporting Guideline Checklist:

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care, 19,* 349–357. doi:10.1093/intqhc/mzm042

No	**Item**	**Guide questions/description**	**Page number(s)**
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	P.10 of the clean copy of the revised manuscript
2.	Credentials	What were the researcher's credentials? *E.g. PhD, MD*	Title page
3.	Occupation	What was their occupation at the time of the study?	Pages 7-8 of the clean copy of the revised manuscript
4.	Gender	Was the researcher male or female?	P.10 of the clean copy of the revised manuscript
5.	Experience and training	What experience or training did the researcher have?	P.10 of the clean copy of the revised manuscript
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	P.8 of the clean copy of the revised manuscript
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? e.*g. personal goals, reasons for doing the research*	P.8 of the clean copy of the revised manuscript
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? e.g. *Bias, assumptions, reasons and interests in the research topic*	Pages 7, 8, 26 of the clean copy of the revised manuscript
Domain 2: study design			

No	Item	Guide questions/description	Page number(s)
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? *e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis*	Pages 6-7 of the clean copy of the revised manuscript
Participant selection			
10.	Sampling	How were participants selected? *e.g. purposive, convenience, consecutive, snowball*	Pages 8-9 of the clean copy of the revised manuscript
11.	Method of approach	How were participants approached? e.*g. face-to-face, telephone, mail, email*	Page 9-10 of the clean copy of the revised manuscript
12.	Sample size	How many participants were in the study?	P.12 of the clean copy of the revised manuscript
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	Not applicable
Setting			
14.	Setting of data collection	Where was the data collected? e.*g. home, clinic, workplace*	Pages 9-10 of the clean copy of the revised manuscript
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	Pages 9-10 of the clean copy of the revised manuscript
16.	Description of sample	What are the important characteristics of the sample? *e.g. demographic data, date*	Pages 12, 34 of the clean copy of the revised manuscript
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Pages 10, 32 of the clean copy of the revised manuscript
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	P.12 of the clean copy of the revised manuscript
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	P.10 of the clean copy of the revised manuscript

No	Item	Guide questions/description	Page number(s)
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Pages 7, 8, 26 of the clean copy of the revised manuscript
21.	Duration	What was the duration of the interviews or focus group?	P.10 of the clean copy of the revised manuscript
22.	Data saturation	Was data saturation discussed?	P.10 of the clean copy of the revised manuscript
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	P.12 of the clean copy of the revised manuscript
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	P.11 of the clean copy of the revised manuscript
25.	Description of the coding tree	Did authors provide a description of the coding tree?	P.33 of the clean copy of the revised manuscript
26.	Derivation of themes	Were themes identified in advance or derived from the data?	P.11 of the clean copy of the revised manuscript
27.	Software	What software, if applicable, was used to manage the data?	P.11 of the clean copy of the revised manuscript
28.	Participant checking	Did participants provide feedback on the findings?	P.12 of the clean copy of the revised manuscript
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.*g.* *participant number*	Pages 13-21 of the clean copy of the revised manuscript
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Pages 13-21 of the clean copy of the revised manuscript
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Pages 13-21 of the clean copy of the revised manuscript
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Pages 13-21 of the clean copy of the revised manuscript