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SARS-CoV-2 infection and COVID-19: The lived experience and perceptions of patients in isolation and care in an Australian healthcare setting



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Background: Isolation and quarantine are key measures in outbreak management and disease control. They are, however, associated with negative patient experiences and outcomes, including an adverse impact on mental health and lower quality of care due to limited interaction with healthcare workers. In this study, we explore the lived experience and perceptions of patients in isolation with COVID-19 in an Australian healthcare setting.

Methods: Using a phenomenological approach from a Heideggerian hermeneutical perspective, we conducted individual semistructured interviews with the first 11 COVID-19 patients admitted to a designated COVID-19 facility in Australia. Interviews were audiorecorded, transcribed verbatim, and imported into NVivo 12 for coding and analysis.

Results: Participants' lived experience and perceptions of COVID-19 were represented by 5 themes: "Knowing about COVID-19," "Planning for, and responding to, COVID-19," "Being infected," "Life in isolation and the room," and "Post-discharge life." Within these, participants conveyed both positive and negative lived experiences of infection, isolation, and illness. The contextual aspects of their social and physical environment together with their individual resources contributed to the framing of their planning for, and response to, the outbreak, and were important mediators in their experience.

Conclusions: Findings from this study provide a valuable insight into the lived experiences of patients with COVID-19, which reflect those of patients with other infectious diseases who require isolation.

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On March 11, 2020, the World Health Organization declared COVID-19 a global pandemic.¹ The pace of the outbreak driven by the high infectivity of the SARS-CoV-2 virus² coupled with the absence of a specific treatment or vaccine³ and widespread human-to-human

transmission^{4,5} has necessitated stringent quarantine and infection prevention and control measures to contain it and mitigate its effects on a global scale not seen in more than a century. Many countries have implemented strict measures including national lockdowns, closures of airports and borders, cessation of regional, national, and international travel, mandatory self-quarantine for returning overseas travelers, closure of businesses and offices with individuals working from home, and social and physical distancing of residents and communities.

There are clear and intended public health benefits to implementing source isolation and quarantine measures for outbreak management and disease control. However, managing individual patients in

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isolation under stringent infection control precautions has both positive and negative outcomes.^{6–11} Some patients view having privacy via a single room as a positive experience.^{6,11} Others report negative health and social outcomes including stress, anxiety, depression, loneliness, avoidance behaviors, anger, and risks to physical health.^{6,7,10,12–14} In previous studies of the experience of source isolation for infection with multidrug resistant organisms such as multi-drug-resistant tuberculosis and vancomycin-resistant enterococcus patients commonly reported feelings of anger, anxiety, uncertainty, depression, and stigma.^{8,10,15,16} Patients under contact precautions for healthcare-associated infections have also reported poor staff coordination and lack of respect for their needs, resulting in unsatisfactory patient care.¹⁷

Patients with suspected or confirmed COVID-19 infection are managed using a combination of standard and transmission-based (contact, droplet, and airborne) precautions¹⁸ during the course of their illness. These include source isolation measures such as being domiciled in a single standard (S) class, negative pressure (N) class, or quarantine (Q) class rooms with restricted access to staff and visitors. These measures are designed to contain the infection and limit further transmission of COVID-19. While there have been studies on staff experiences of caring for COVID-19 patients and the need for appropriate mental healthcare,^{19,20} there are no published studies on COVID-19 patient experiences in isolation. We now describe the lived experience and perceptions of 11 patients in isolation with COVID-19 in New South Wales, Australia.

METHODS

Study design and methodology orientation

An interpretive phenomenological approach using the core elements of Heideggerian hermeneutical perspective was employed to help explore for meanings of the phenomenon (ie, being in isolation) with the purpose of understanding the patients experience. This offered a holistic method to understand how participants' experiences and perceptions are contextually formed, influenced, and sustained through both having COVID-19 and living in an isolation room.^{21,22} This approach enabled us to understand the totality of participants' lived experience through a blend of meanings and understandings articulated between them and the investigators.

Participants and setting

Study participants consisted of the first 11 patients with confirmed COVID-19 who were admitted to a designated isolation facility in New South Wales, Australia. They were all managed under both standard and transmission-based (contact, droplet, and airborne) precautions. During this phase of the outbreak, all individuals diagnosed with COVID-19 were admitted to hospital for isolation regardless of symptom severity and until meeting clearance criteria. Those who presented with mild clinical symptoms were cared for in a repurposed ward with 11 single patient rooms. Patients presenting more severe illness were managed in a single quarantine (Q) class negative pressure isolation room with intensive care capability and a separate anteroom and exit room, but no natural light or windows. All patients were provided with, and asked to wear, a surgical face mask while in their rooms.

Data collection

Flexible semistructured face-to-face interviews were conducted in February and March 2020, during participants' hospitalization. Interviews were conducted at the bedside and went for between 15 and 45 minutes. Patients were interviewed about: (1) sources of

information they had sought to gain knowledge about COVID-19 and the outbreak; (2) their perceptions and feelings about being diagnosed with COVID-19; (3) their experiences during the course of their treatment and care; (4) their experiences about being treated in hospital for a novel and emerging infectious disease; and (5) their planning and preparedness in relation to the COVID-19 pandemic. Prompts were used to clarify, probe and unpack their responses, experiences and perceptions. Interviews were audiorecorded and transcribed verbatim. Interview transcripts were imported into NVivo 12 for coding and analysis.

All interviews were conducted by the lead investigator (RS) who has expertise in qualitative research, infection prevention and control, infectious diseases, and outbreak management. In accordance with the guidelines¹⁸ by the Communicable Diseases Network Australia, the interviewers employed contact and droplet precautions, including donning of recommended personal protective equipment, to conduct the interviews.

Data analysis

The analysis was based on Diekmann, Allen, and Tanner's²³ seven-step method. To gain an overall understanding of the data, transcripts were read, and audio files of interviews were listened to. Summaries of each transcript were drafted, and early potential themes were identified. Preliminary findings were compared, discussed, and agreed to identify early themes in the dataset. All transcripts were then re-read and reviewed. Identified themes and patterns in data were verified through discussion, and transcripts were re-read to link relationships and overlaps between themes. Findings were integrated, synthesized, and reported using consolidated criteria for reporting qualitative research (COREQ).

Rigor

Lincoln and Guba's²⁴ criteria were used to ensure qualitative trustworthiness. Credibility was achieved as the investigators are experienced researchers and clinicians in infectious diseases and are extensively familiar with the care setting and context of the participants. Co-constitution technique was used by the interviewer to verify participant meaning during the interview.²⁵ Dependability occurred as the expert interviewer was directly involved in revising and categorizing of the primary output. The team-based data analysis enabled confirmability of the findings as being clearly derived from the data, with a documented research path. Generating thick descriptions of the participants' lived experience in this setting within NSW afforded transferability to other contexts or settings. Team meetings were used to exercise reflexivity where the investigators examined the relationship between their individual conceptual lenses, assumptions, values and preconceptions, and the research.

Ethical considerations

Human Ethics Research Committee ethics approval was obtained from Western Sydney Local Health District Human Ethics Research Committee (2020/ETH00285) and the research was conducted in accordance with the approved protocol. Informed consent was obtained from all patients, with no complaints raised or reported and no participant withdrawal of consent.

FINDINGS

There were eleven participants (4 females and 7 males) aged 27–61 years in the study. Two reported comorbidities; one with hypertension and hypercholesterolemia, and the other with hypercholesterolemia and fatty liver. All except 2 had recently traveled overseas to

confirmed COVID-19 epicenters. Five themes encapsulated the lived experiences and perceptions of the COVID-19 patients in the designated isolation facility in New South Wales, Australia.

Theme 1: “Knowing about COVID-19”

The participants' lived experience of COVID-19 was anchored to commercial news and other similar media forums. They had made considerable efforts to obtain up-to-date information from different sources about the global epidemiology, clinical characteristics, and recommended infection prevention and control measures for COVID-19. Primary sources of information included mass media (television and radio), social media (namely Facebook, Instagram, WhatsApp, and Telegram), and online resources (Google and other web search tools). Importantly, participants reported a clear preference for information from official sources citing their trustworthiness and reliability. Some emphasized that they obtained reliable information from scientific articles and online resources provided by the Australian Government, the World Health Organization, and the United States Centers for Disease Control and Prevention. As one participant remarked:

There is lots of information and you got to be really, be picky in where you get the info from. So I started reading the World Health Organization incident reports as well. Because we were travelling, so obviously I wanted to make sure that the risk was factored into our travel (Participant 10)

For other participants their experiences of COVID-19 were defined by a mistrust in official sources of information, and a clear preference for nonofficial forms of media that were not sanctioned by governments and authorities:

Media [is] concerned about this kind of disease and they maybe censor something about that to not panic people. So, social media is better because people talk together, So, it is more real than maybe from media, because media is observing very different things to don't panic the public. (Participant 7)

Interestingly, the experience of many participants was defined by their criticism of social media platforms that sensationalized COVID-19 more so than through official news and media channels:

[COVID-19 news was] just a bit pervasive in social media. It is a bit I think sensationalised compared to what scientist are saying. I think social media was much more sensational in terms of its coverage. (Participant 9)

For the participants the trustworthiness of the information they sourced about COVID-19 was fundamental to their experience for planning for COVID-19.

Theme 2: “Planning for a response to COVID-19”

In response to their diagnosis of COVID-19, participants indicated they had planned across 4 different levels: individual, family, community, and society. Individual-level planning encompassed the adoption of precautionary measures to minimize the risk of spreading the infection. Self-isolation and home-quarantining were practiced by some participants before admission to hospital as they considered them to be effective measures to ensure the health and safety of their close contacts (eg, family members). As one participant remarked:

In the meantime, I was separating myself from the rest of the family and stayed in a room with masks and gloves on. Luckily, my daughter went to the hospital yesterday together with her father, where she was tested negative for Corona. (Participant 4)

Other measures taken by participants included cognitive preparedness for becoming unwell with COVID-19 and concealment of the diagnosis to avoid distress and anxiety in non-immediate family members.

Family-related responses and planning were reported by almost all participants. Several participants elucidated that their family proactively provided support to them over the course of their diagnosis and hospitalization. Family members also undertook active precaution measures and engaged in home-isolation, as the following participant's remark illustrates:

My daughter wanted me to [stay away] for two weeks. So, I didn't go anywhere. So, then my son-in-law suggested me “Mom! You were [overseas] with pneumonia, so you were to check for Coronavirus, because you had no symptoms, but you can go bad with the virus. That's why I came here last Thursday, and Friday I go to [private diagnostic laboratory] to check it. (Participant 5)

Participants who had recently traveled overseas described their observation and adherence to some community-initiated measures during their trip. One participant outlined changes in daily routines and social life:

In [name of the country], from one month ago they cut [sic] going out and to see each other in their home, having party, everything as they can. Handshaking, they cut absolutely handshaking. There's no handshaking as I've seen. (Participant 7)

In terms of planning their responses to COVID-19 at a societal level, participants' experiences strongly reflected the role and impact of media. For some participants their experience featured appreciation for the media in increasing public awareness about COVID-19:

The news is good to make public realise there is a new virus. People should take serious about this one. . . I personally think news is good. (Participant 3)

For these participants, the increased public awareness of COVID-19 via news outlets in their community positively defined their experience. However, for others their experiences of COVID-19 were defined by societal features that were negative and destructive, particularly with respect to stories in the news and other media of individuals and groups attributing the disease to specific racial and ethnic groups, as explained by one participant:

The media really spun it as like something to be really fearful of. There was a lot of hysteria. I work in the city and you start seeing people wearing masks on the train. All of the sudden you are conscious of people around you, people are coughing around you and you are like ‘does he have the virus’ you know, like, move seats and you know, step away, and back then it was all to do with China, so it was unfortunately a lot of people racially, they racially profled the disease to limit it to Chinese people (Participant 10)

This negative and destructive societal feature was particularly relevant to them coming to terms with their diagnosis of COVID-19 and “being infected.”

Theme 3: “Being infected”

All participants expressed feelings of shock when they learned of their diagnosis. The feeling of being diagnosed with laboratory-confirmed COVID-19 resulted in anxiety, shock, and doubt, and was described by participant as being “surreal”:

It was a bit surreal that I actually got infected by it... I couldn't believe I had actually contracted the virus... that I tested positive. And it's like for the last few weeks we have been seeing Coronavirus in the news non-stop. Every day you check the news, the headlines are Corona. And then you are like 'Oh my god, I actually caught it' (Participant 10)

In all cases, participants did not initially consider themselves at risk of contracting COVID-19 for a variety of reasons. First, all 11 participants indicated that they, for the most part, had mild and nonspecific symptoms, such as cough, low-grade fever, and body pain. This led their first treating doctors to consider other conditions such as the common cold, flu, and Dengue Fever. The following quote illustrates this:

I felt weak so I thought I had a cold from other person. But last of January when I went overseas I was so sick, so two days later I went to the hospital. That time I just think the mosquitos bite me anywhere so I think I was a Dengue fever. I met the doctor, and [said] I wanted to check for Dengue, so she checked me for Dengue and flu. (Participant 5)

Second, the incongruity between participants' actual experience of their illness and the clinical characteristics of COVID-19 reported in the media led them to believe that their clinical signs and symptoms were inconsistent with COVID-19. The following remarks illustrate this:

Even though I actually get infected with the Coronavirus, I think my Coronavirus might be different from what the media says. Most of the media tries to exaggerate the seriousness of the illness but I do not think so. The information is not 100% consistent. (Participant 2)

Third, it was hard for participants to believe that they had contracted the infection because they reported taking a range of precautionary measures when they first heard about COVID-19, such as additional hygiene practices, as one participant described:

I was assuming I wouldn't get it [the disease], but I eventually got it. But I was taking precautions. I was wearing masks, gloves... I was feeling confident that I was taking all the precautions, and I didn't think that I could catch it. (Participant 4)

For many of the participants the lived experience of “being infected” with COVID-19 brought negative emotions and feelings. The dominant concern from participants was that they may have, or were likely to, spread infection to others, in particular family members and friends. There was also concern about perceived stigma from public and others within their inner circle. As illustrated in the excerpts below, some participants experienced feelings of guilt for consuming hospital resources (eg, beds and personal protective equipment) and for potentially exposing the healthcare workers to the infection:

I made my own bed. I feel bad about the staff, I don't want them to... you know. I feel guilty cause like they shouldn't need to put themselves at risk for me. (Participant 8)

I'm getting guilty about the poor staff have to all the time wearing and taking off something. I'm a bit so sensitive about, how can I say... environment when I see lots of plastic things have been used in. So, I'm worried about some things like these. (Participant 6)

Nonetheless, most participants said that they were not afraid of having COVID-19. Participants understood the likely clinical course of disease and knew about patient groups at greater risk of severe morbidity or mortality. Most participants described their symptoms as not being severe, and expected to make a full and speedy recovery:

I don't feel any of the heavy symptoms that a lot have reported in, with other patients. Although I don't know how long it's still to go. It's anyone's guess really. But I do feel I am up for a good recovery and you know, just go home then. (Participant 9)

The experience of “being infected” was strongly associated with the physical features of the care environment.

Theme 4: “Life in isolation, and the room”

The experience of being a COVID-19 patient in an isolation facility brought with it both positive and negative experiences. For some of the participants, isolation and quarantine practices were positive experiences and a clear reflection of the professionalism and quality of care being provided, which enhanced their confidence in the healthcare system and helped to ameliorate their initial concerns with being infected:

The media had spread news about this virus which were really scary, and it is absolutely new so at the beginning I felt scared... I am actually very happy with the isolation in terms of facilities and professionalism that all nurses and doctors provided. (Participant 2)

Nevertheless, for others, their lived experiences of being under source isolation brought a range of negative emotions and effects due to a lack of social interactions, losing the track of time, and being physically isolated with limited mobility:

Isolation has been mental painful. I was in the hospital for 6-7 days in that isolation room. Because I had nothing, no windows, no one to talk to. It's very cold in the room... is very hot, you have to have certain temperature, no TV, nothing. The first couple of days were fine, but day 3 or 4 got a bit more depressed in a way. We got no interaction. I don't know what time it is, cause there is no window. I think one night we got a big storm and that was the only thing I heard from the outside world because the sound went through... But I just sleep, I can't exercise, I have to stay in bed. So, a bit depressing at time. I mean, I have never been in jail before, but I would assume that it would be [a] similar experience. A little room. (Participant 1)

In the experience of another participant, the physical characteristics of the hospital rooms led to the feeling of being disconnected from the world outside:

There is nothing in here, no clocks, no TV, no mirrors. [having a clock on the wall] would make it better cos I can track the time and I would get to know how I'm up to... It's now several days that I haven't seen myself in a mirror... so I can see if I'm getting better or worse. (Participant 4)

Some participants noted that the physical layout of the hospital rooms restricted their ability to move around or do physical activities. One participant explained that, in the context of having no definite

cure for COVID-19, being isolated in hospital had deprived him from accessing other sources of therapy that they would otherwise seek:

Given there is no cure or no medicine, we should try and focus on the natural remedies, like the old mother's mentality: you should be having lots of warm drinks or herbal tea... I don't have the facility to actually do that, but if I was at home, I would. And I actually believe in that stuff. Cos' that's the stuff that helps you get through a cold when the antibiotics can't help you... Eating lots of onions, eating lots of fresh fruits with vitamin C. Things like that. I feel I am missing out and I feel that's the stuff that would naturally help my body to heal. (Participant 10)

For many of the participants, the experience of care under transmission-based precautions made interactions and communications with healthcare staff difficult. While they reported experiencing trust and confidence in their doctors and nurses, they expressed a desire for more information about their illness, treatment, and prognosis from their treating doctors. Some participants perceived that their chance to communicate with healthcare workers could have been undermined due to staff workload, time-pressure in the ward, and healthcare workers' possible fear of contracting the virus through longer interactions with patients:

I actually have requested a couple of times and they said "we/the doctor will come back". Doctors are afraid to come into the room I think, and they spend very very little time, which I guess is understandable as well (Participant 8)

In this setting, some participants with limited proficiency in English struggled with the language barrier. As one participant described, she was unable to convey all her needs to the healthcare workers because she was "not able to communicate with them." (Participant 4).

Psychological consequences of being under source isolation became more significant as the duration of hospitalization increased, as one participant described:

I have been here for a week, and I have had very limited social contact anyway... I am just like emotional, I can feel like I am slipping my rational thoughts which is just... you know, that's normal for me anyway. Like if I get tired, I am more likely to cry, like anybody... Right now, I am just so tired and delirious, and I guess that instinct takes over and you don't really think things logically. (Participant 8)

To minimize the negative psychological effects of isolation, some used adaptive coping practices. All participants had smartphones or similar devices which they used to contact family and friends, connect to the world outside, and track days and time. One participant outlined her system of belief and described how she used the opportunity of being alone to reflect and gain a better understanding of others struggling with medical conditions:

I think the God gave me a time to [get] close to God. I recognise here there are very difficult patients, many many difficult patients. They have cancer, they have the problem with family and children. I think I am so thankful to God. I have just a short time experience for that, because I can understand others (Participant 5)

Participants similarly foreshadowed using adaptive coping mechanisms after discharge from hospital.

Theme 5: "Post-discharge life"

All participants anticipated making a full recovery from COVID-19 and expressed this experience as life post-discharge. Many explained that their experience had led to adopting new behaviors including better hygiene practices. Their experience resulted in them wanting to make changes to their lifestyles to boost overall health and improve the immune system. Many expressed a concern about remaining infective or re-infection in relation to post-discharge life:

Actually, the main thing I'm worried [about], I'm not sure if I finish these fourteen days, it means... now Australia is starting the Winter... so it means I'm not getting again catching the Coronavirus? Re-infection! I'm just worried about that, because now my husband was negative, my kids [were] negative, so I'm worried 'oh, so if they get that, then me get that, and again this process, 14 days isolated. (Participant 7)

DISCUSSION

Source isolation and quarantine measures are instruments for outbreak management and disease control, and existing research reports both positive and negative outcomes following their use.^{6-8,11} The findings of this study of the experience and perceptions of COVID-19, the first of its kind, are consistent with existing literature on experiences during isolation for an infectious disease.^{6,8-10,12,15,16,26} Source isolation helps to contain the infection and offers a satisfying level of care and privacy for patients.^{27,28} Notwithstanding this there are negative and unintended psychological consequences of isolation such as anxiety, depression, and aggression which are well documented in the existing literature. Having to deal with the negative feelings generated by contracting a highly infectious novel virus and the psychological effects of isolation can have detrimental impacts on patients' coping capacity and self-esteem.^{6,29} Previous research indicates that patients' perceptions and experiences in isolation are gravely influenced by the physical characteristics of their environment.^{6,26,28} Some of the practical ways to minimize the negative and unintended consequences of isolation include provision of sufficient physical space to walk around, allowing more activities, and having large windows to enable the participants to connect to spaces outside their room. The Q-class rooms where some of the participants were domiciled had no windows and no natural light. Our findings also illustrate the importance of measures that can provide effective sensory stimuli to patients who are physically isolated.

The Heideggerian hermeneutical perspective employed in this study led to a holistic understanding of the COVID-19 patients in the context of isolation, as we were able to capture the nuances and key elements in the totality of their experiences and perceptions. Interestingly, the insight into how the participants planned for, and responded to, COVID-19 along the trajectory of their experience suggests several tiers (individual, family, community, and society) in the scope of their resources and capabilities. Taking into consideration the contextual aspects of participants social and physical environment together with their individual resources can nurture a holistic model for patients planning and response, which will be useful for wider public health programs. Further research can employ social-ecological perspective to gain a better understanding of the dynamic complexity and the contextual reality that surrounds the patients.^{30,31}

Developing and implementing models of care for COVID-19 and other high-consequence infectious diseases requires that the negative and unintended consequences of isolation be minimized. Changes to the physical environment and strategies to address communications barriers between staff and patient can further enhance

the moral elements in the ethics of care,^{17,32} resulting in better outcomes for patients.^{6–8} Providing specialized mental health, social support, and interpreter services should also be considered in addressing special needs of patients in isolation. Further studies are needed to explore the advantages and disadvantages of other modes of isolation (eg, home isolation) and benchmark their effectiveness in preparation for future large-scale infectious diseases outbreaks.

Having a multidisciplinary team of investigators to interpret the data produced a rich description of the lived experiences and perceptions of COVID-19 patients during a global pandemic. However, the study does have limitations. Interviews were conducted with participants during their hospitalization, and it was not possible to follow-up with them post discharge to conduct member-checking.²⁴ Instead, we used the re-constitution technique to ensure credibility.²⁵ We also acknowledge that participants' cultural background and their sociocultural context influences their experiences, and further sociocultural research should examine this.

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