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EXPERIENCES OF PEOPLE RECOVERED FROM COVID-19 IN BANKE DISTRICT, NEPAL: A QUALITATIVE STUDY

Shalabh Shah[1]*, Bijay Thapa[1], Ambika Thapa Pachya[1], Madhusudan Subedi[1]

[1]Patan Academy of Health Sciences, Lagankhel, Lalitpur, Nepal

*Correspondence: Shalabh Shah, shalabh.shah@gmail.com

ABSTRACT

Background: Coronavirus disease 2019 (COVID-19) is an infectious disease caused by a newly discovered coronavirus (SARS-COV-2). The aim of study was to explore experiences of people recovered from COVID-19 in Banke district, Nepal.

Methods: This is a qualitative study. A semi-structured interview guide was used to conduct qualitative in-depth interviews from the participant with result positive for COVID-19 during the period of September to October 2020.The participants were purposively selected from the isolation centre of Banke district. Twenty-four in-depth interviews were conducted through telephone calls. Data was analysed using Colaizzi's descriptive phenomenological method. The experiences of the COVID-19 recovered people were analyzed in three themes- treatment experiences, emotional experiences, and experiences of stigma.

Results: Some of the treatment experiences included experience during symptoms, diagnosis, communication of test results, transportation, care from health workers and remedies. The emotional experiences included the feeling between test and result, feeling after result and feeling in isolation center. Similarly, the experiences of stigma included stigma experience in workplace, isolation center and communities.

Conclusion: Participants experienced emotional and psychological problems during different stages of disease. Psychosocial support from family, friends and health workers is helpful to cope stressful situations. Activities like exercise, watching videos and using internet can help to divert attention and help in emotional wellbeing. The findings from the study suggests need to address the stigma in the form of discriminatory behaviours that are prevailing in our society regarding the transmission of disease.

Keywords: COVID-19, COVID-19 recovery, experience, isolation, qualitative study, Nepal

INTRODUCTION

Coronavirus disease 2019 (COVID-19) is an infectious disease caused by a newly discovered coronavirus Severe Acute Respiratory Syndrome Corona Virus 2 (SARS-COV-2).[1] By 28th December 2020 there were 81,186,499 confirmed cases of COVID-19 globally and the total deaths reported were 1,772,838.[2] In Nepal, the first case of COVID-19 was seen on 23rd January 2020.[3] As of now, it has reached to every local government level in the country.[4] By 22nd March 2022, the total number of confirmed cases in Nepal was, 978,196 among them, 11,950 have died and 966,246 have recovered.[4] Responding to the pandemic in Nepal different public health, social and hospital based approaches were applied for the prevention, control and management of COVID-19.[5]

In terms of treatment settings, the current COVID-19 pandemic has called for human resources from different places and departments come together. Frontline health workers like doctors, nurses, laboratory staffs are worried about

their safety well as fear spreading the infection to their family members.[6] They have to face difficulty of managing patients if number of patients in the centre exceeds the resources.[6] The COVID-19 wards have patients from new born to elderly people with co-morbidities. During the initial phase of the pandemic, there was no universal treatment protocol and the treatment protocols were updated regularly based on the scientific findings when new evidence were available.[7] All these factors affect the quality of service that patients in COVID-19 wards receive.

Living in isolation centers for at least two weeks is physically as well as mentally challenging for the COVID-19 infected people. After contracting with the disease, patients are seen experiencing various mental health issues such as fear, insomnia, psychological distress, post-traumatic stress disorders, anxiety and depressive symptoms.[8] Mental health interventions are incorporated along with other interventions in treatment centers. Psychosocial counselling was planned to be provided to patients, family members and health workers through appropriate medium such as group counselling applications in Nepal but whether it was implemented or not is yet to be explored.[5]

A systematic review has also shown that the patients of COVID-19 experience stigma and discrimination.[8] Such discrimination can be done by health workers, family members and community people.[9] It is very important to mitigate fear and discrimination against people who are infected with and affected by COVID-19 disease.[10] It can be helpful in controlling the transmission of disease as people who are stigmatized and discriminated often delay to seek health care and remain in the community undetected. [10]

To fill the gaps seen during the literature review, a qualitative study was conducted to explore the experiences of people recovered from COVID-19 in Banke district, Nepal. The findings are expected to guide stakeholders in improving health care services in isolation centres and rehabilitation of the COVID-19 recovered patients back to the family and community.

METHODS

Qualitative study design was chosen to document the lived experiences of people who recovered from COVID-19. Colaizzi's descriptive phenomenological method was used for the study.[11] The study was conducted among 24 people who had recovered from COVID-19 in Banke district. Only those participants were included in the study who had recovered from COVID-19, were permanent resident of Banke district, were eighteen years or older during the time of the interview and gave consent to participate in the study. Judgmental sampling was used as a sampling method for selecting the participants for the study. The participants selected were from six isolation centers of Banke district. The data was collected during the period of September to October 2020. The context of COVID -19 situation at that time was around ending period of first wave. Institution based isolation centres were in place for the patients infected with COVID-19 during the time of data collection. Participants recovered from COVID-19 at the isolation centre were recruited as study participants. People from different backgrounds, educational status, ethnicity, and gender were included. The total number of In-depth Interviews (IDIs) '24' was deemed enough by the researcher for information saturation. The researcher felt that no new experiences, dimensions, relationships emerged after that point. So, the data collection was stopped after conducting 24 IDIs.

Interview guide approach with a semi-structured open-ended guideline was used for the IDI of participants.[12] All IDIs were taken through telephone calls to avoid contact. Mobile phone was used for recording the interview. All the participants were taken informed consent for recording the interview. Field notes was taken in notebook for collecting audio observations like voice tone, pause during interview to enrich the information covered by the audio recordings for each participant. It was made sure that the interview was taken in a quiet place with minimal background noise. To ensure this, after the participants agreed to participate in the study, suitable time was taken with them. They were called in that agreed time for the interview. The

duration of each interview ranged from 20 to 45 minutes as per the circumstances. It was also ensured that there was nobody around the interviewee while asking the sensitive questions about stigma and discrimination. The recorded interviews were transcribed in English language and transcript of each interview was prepared. Colaizzi's descriptive phenomenological seven steps were used for the analysis of interview transcripts.[11] Transcripts were read multiple times until the researcher was familiar with the text. Significant statements in each transcript were marked by the researcher. Meanings of significant statements were generated, and codes were finalized. After the coding was completed, similar codes were grouped to form themes. (Table 1)

Table 1: Themes and subthemes

Themes	Subthemes
Treatment experiences	Symptoms
	Diagnosis
	Test Result Communication
	Transportation
	Facilities in isolation centres
	In kind support
	Care from health workers
	Remedies
	Difference from hospitalization in other diseases
	Satisfaction
Emotional experiences	Feeling between test and result
	Feeling after result
	Feeling in isolation centre
	Activity in isolation centre to divert attention
	Emotional support
	Home isolation
Experiences of stigma	Stigma in workplace
	Stigma in isolation centre
	Stigma in communities

After the finalization of sub themes and themes, detailed exhaustive description of the findings of the study was done. The researcher subsequently eliminated redundancies in the answers and condensed the exhaustive description down to a short, dense statement that captured only those aspects deemed to be necessary to the structure of the phenomenon. R package for Qualitative Data Analysis (RQDA) was used for the process which is a freely available computer application for qualitative data analysis.[29]

Guba's constructs of rigor was used to ensure the trustworthiness of the study.[13] The tool was developed with the content experts and extensive literature review. Member checks of three transcripts were done with the participants who agreed with their transcripts and their statements. A total of 85.7% of the codes were agreed between two independent researchers using percentage positive method.

RESULTS

Socio-demographic information of participants

A total of 24 participants were recruited in the study with mean age of 36.42 years (19 to 57). Among the total participants, 16 were male and eight were female. Sixteen participants were from Nepalganj sub-metropolitan city, four were from Khajura rural municipality, three were from Kohalpur municipality and one participant was from Duduwa rural municipality. (Table 2)

Table 2: Socio-demographics of participants

Code	Age	Sex	Residence	Ethnicity	Religion	Education	Occupation
P1	48	F	Nepalganj-11	Dalit	Hinduism	Lower secondary	Ward member
P2	46	M	Nepalganj-5	Madhesi	Hinduism	Higher secondary	Business
P3	34	F	Nepalganj-10	Madhesi	Hinduism	Illiterate	Homemaker
P4	25	M	Kohalpur-3	Janajati	Hinduism	SLC	Government employee
P5	29	M	Nepalganj-1	Brahmin	Hinduism	Graduate	Business
P6	41	F	Nepalganj-2	Chhetri	Hinduism	Graduate	Government Employee
P7	47	M	Khajura-3	Dalit	Hinduism	Primary	Foreign employment
P8	19	M	Khajura-4	Dalit	Hinduism	SLC	Foreign employment
P9	25	F	Nepalganj-5	Janajati	Buddhism	SLC	Homemaker
P10	29	M	Nepalganj-13	Janajati	Hinduism	Higher Secondary	Private Job
P11	48	M	Nepalganj-9	Chhetri	Hinduism	Lower secondary	Driver
P12	44	M	Nepalganj-15	Sikh	Sikhism	SLC	Driver
P13	29	M	Khajura-3	Janajati	Buddhism	SLC	Government employee
P14	38	M	Kohalpur-2	Brahmin	Hinduism	Lower secondary	Foreign Employment
P15	46	M	Nepalganj-10	Chhetri	Hinduism	Graduate	Business
P16	30	M	Kohalpur-11	Chhetri	Hinduism	Graduate	Private Job
P17	28	F	Nepalganj-4	Brahmin	Hinduism	SLC	Private Job
P18	41	M	Nepalganj-9	Madhesi	Hinduism	Graduate	Private Job
P19	26	F	Khajura-4	Chhetri	Hinduism	Diploma	Government employee
P20	57	F	Nepalganj-10	Janajati	Hinduism	Diploma	Government employee
P21	37	M	Kohalpur-6	Brahmin	Hinduism	Lower secondary	Driver
P22	33	F	Duduwa-5	Thakuri	Hinduism	SLC	Business
P23	25	M	Nepalganj- 2	Janajati	Hinduism	Higher secondary	Private Job
P24	49	M	Nepalganj-9	Janajati	Buddhism	SLC	Business

* M = Male, F = Female, SLC = School Leaving Certificate

Theme 1: Treatment Experiences

This theme covers symptoms, diagnosis, test result communication, transportation, facilities in isolation center, in-kind support, care from health workers, remedies, and satisfaction.

Most of the participants experienced mild symptoms of the disease. Fever, loss of taste and smell, and cough were the most common symptoms reported. Some participants didn't experience any symptoms at all.

I had no sense of smell and taste, had fever and cough. P19

I didn't have any symptoms, so I did not feel any difficulty. P16

All the participants were conducted Reverse

Transcription Polymerase Chain Reaction (RTPCR) test for their diagnosis to be confirmed. Most of the participants didn't experience any difficulty for conducting their COVID-19 tests. Some participants complained about long waiting time and pain while giving nasal swab.

… there was no difficulty for COVID-19 test. P21

When they took my swab, they inserted nasal swab very deep. It was really painful. I don't know if it is required or not to take swab in such a painful way. P15

Most of the participants were contacted in telephone and were informed about their result. Some of them were messaged and others checked their result online.

Health office informed me. They took our contact details during the swab collection. They called me after I was positive to inform me officially. P13

I was messaged in my phone. I also received call from health office. P21

Ambulance was the most common mode of transportation to the isolation centres. Some patients also used private vehicles to reach isolation centres.

Ambulance came to take me. I went in ambulance to isolation centre. P10

They asked us if they needed to send ambulance to go isolation centre, I said you don't need to send me I will go to the isolation centre by myself in my motorbike. P11

Most of the participants were happy with the arrangements of isolation centre. Lack of cleanliness and quality of food in isolation centres were issues for some of the participants.

… cleanliness was an issue. We used to clean our room every day and kept the waste outside the room. They did not collect it for 4-5 days. P14

Food given there was not tasty. We told them to make the food better. P2

Hygiene kits including different items were provided to patients in isolation centres. One participant was not happy for the fact that he had to share thermometer with other patients for few days.

…they had given all the necessary equipment like mask, net, gloves, and sanitizer. And for the female patient they had provided pads and other necessary things. P1

We were given a kit. There was a thermometer in the kit. We used to take our temperature ourselves. P9

Health workers in the isolation centres monitored patients remotely. Most of the patients felt that it would have been better if there was more physical presence of health care workers (HCWs) using 'Personal Protective Equipment (PPEs). Patients with serious symptoms in COVID-19 hospitals were regularly monitored in physical presence of health workers.

There were health workers who monitored us remotely. They didn't visit us physically in the isolation centres but we were being monitored by the health workers in our isolation room. I didn't feel good that they never came to visit us physically, not even once. Even their few words can help a lot emotionally. They could have come maintaining physical distance and using PPEs. P10

They used to regularly monitor our health status. Nurse used to come in cabin to monitor us. They used to monitor our temperature and oxygen level. P13

Most of the participants who were asymptomatic or with mild symptoms were not given any medications. Participants with symptoms were given symptomatic treatment. Almost all participants were consuming herbal/traditional medicines during their stay in isolation centres.

I had taken a water boiler, 'gurjo', turmeric powder and ginger for preparing the drink which I and my son consumed. P24

Not having specific treatment for the condition and not being able to meet friends and relatives were the major differences between being isolated and being hospitalized with other disease condition for most of the participants.

In other cases, friend and relatives come to meet you. But in this case, you are all alone and cannot meet your friends and relatives. P22

Most of the participants were satisfied by their overall experience of their stay in isolation centres.
I was satisfied. We didn't have any difficulty at all. We received the care that we needed. P4

Some participants were not satisfied with the services in isolation centres. They said:

I was not satisfied because they sent me home without testing. I would have felt relief if my test came negative. But they said you don't need to test after staying in isolation for two weeks. P3

Most of the participants were satisfied with the treatment services they received in the isolation centres. Some of the participants were not satisfied with cleanliness, quality of food, not being tested before being discharged and health workers of the isolation centres.

Theme 2: Emotional Experiences

This theme covers feeling before and after diagnosis, feeling in isolation center, activities done in isolation center to divert attention, emotional support, home isolation, and feeling after recovery.

People with symptoms of COVID-19 were more worried and scared after they gave their swabs and were waiting for their results. Other participants with no symptoms were not worried and scared.

I was very much afraid about the result. I was praying for the god that the result to come negative. P1

I didn't feel any sort of fear or anything. I was confident about my immunity. I didn't have any symptoms and I didn't think I was sick. P8

Most of the participants were scared after they were diagnosed positive with the disease, thinking they would die because of the disease.

I was afraid when I came to know I was positive because I didn't know if I would live or die. P9

Feeling of loneliness was the most common among participants in isolation centre, especially in the first few days of stay.

I had never stayed alone, far from my family for such time. After 4-5 days I started feeling lonely and I was worried. P18

During the first few days it was difficult. As I didn't know anybody there and I did not know how my stay was going to be. It became easier after few days. P13

Participants performed different activities during their stay in isolation centre as a coping strategy to divert their attention away from COVID-19 and to feel better. Participants commented:

I used to do yoga and meditation and bath daily. I also regularly consumed hot water with lemon and honey. I used to read newspapers, watchTV and talk to my friends and relatives in home. P15

I used to do my official work during my isolation centres. I also used to watch TV and internet videos. I had also taken a novel with me. I read novel during my stay there. P16

All the participants in the isolation centre received psychosocial support from the family members. They also received emotional support from health workers and other government officials.

I used to talk regularly with my family members in videocalls which helped me a lot during my stay in isolation centre. P10

Hari 'dai' (name changed, government official) gave me psychosocial support. He said you don't need to worry, if you have any complications, we are there to take care of you. P3

Almost all the participants took extra precautions by staying in home isolation for a week after being

discharged from the isolation centres as they were worried of spreading the disease to others.

After I returned, I stayed in home isolation for a week. I avoided eating food in the same plate with my family. P18

I remained in home isolation for another 1 week. And then I did PCR test and I was negative. I joined office only after I was negative. P23

Participants were more cautious and scared when they were in public places after their recovery and returning from isolation centres. Some participants felt that the disease was not so serious as shown in the news.

I am more cautious these days. I am scared all the time and have a fear when I'm in public places. P18
Sometimes I feel it is just a scam to make poor people poorer. If we are not allowed to do business, it's better to kill us. P15

To summarize, participants felt emotional turmoil in different stages of the disease. They were more worried in the initial phase of the disease. Different self-coping mechanisms adopted by the participants, emotional support from health workers and family members helped them feel better emotionally.

Theme 3: Experiences of Stigma

This section covers stigma in isolation center, stigma in community, and stigma in workplace.

Some participants did not feel any kind of discrimination during their stay in isolation centres whereas others felt some discrimination. Participants said:

No one used to come near us. They used to give us the food on the stairs. They used to make announcement when the food arrived, and we had to take our food from stairs. When the water jars used to come, we had to take it up to our room. They didn't even help us to take the water to the room. P1

…when bringing the food, they used to keep that on the staircase. We are human beings and have feelings, we are not animals to be treated like that. P2
Most of the participants experienced discrimination in their community. Participants also mentioned that things are getting better with time and there is less discrimination compared to the time when they were just discharged.

Some of the people maintain distance from me as they know I was COVID-19 positive in the initial days after my return from the isolation centre. The kids stopped playing with my children. P14

I feel people are more dangerous than this disease. If a dog is hit in road by an accident, other stray dogs go near to it and see how it is doing. People are even worse than dogs. I feel being born as an animal is better than being humans. If anybody is positive, I think he should remain in home isolation instead of going to isolation centre because the way people treat you when they know you are COVID- 19 positive, will kill you. P15

Most of the participants did not experience any stigma after they returned to their workplace following their recovery. However, some experienced stigma in their office/workplace from their colleagues.

… didn't face any stigma or discrimination at all. I was welcomed with tika by my colleagues after I was discharged from the isolation centre. P21

All my colleagues in office started going far from me. They didn't come near to me. P12

To summarize, some participants felt being discriminated in isolation centres. Most of the participants felt some discrimination in their community after they returned from the isolation centres. Few participants felt discrimination in their workplace.

DISCUSSION

The study explored the experience of COVID-19 patients after their recovery using phenomenological methods during the early phase of the pandemic. Most of the participants of the study were happy with the facilities provided in isolation centers. A similar study was conducted in Japan where, contrary to our study findings, patients complained about lack of facilities like Wi-Fi, and space for exercise in hospital.[14] However, the living arrangements and health care facilities were acknowledged by the patients.[14] The patients also complained about the quality of the meals which is similar to our study findings.[14] A study conducted in Taiwan suggested that the patients felt the living condition in quarantine was not satisfactory as it was cold in nights, nuisance of mosquitoes, poor availability of food and water.[15] They were not happy with the inconvenient toilet access which is similar to our study findings.[15] Similar to our study findings, patients in an isolation centre in Rupandehi were provided thermometer, masks and gloves.[16] Similar to our study findings, vital signs of patients were reviewed by health workers and provided video consultation in other countries.[17,18] Patients of a quarantine center in China consumed a lot of hot water along with traditional medicine as there were no specific medications, similar to our study findings.[19] To improve the experience of patients in isolation centers, cleanliness in the isolation centres should be improved, quality of meals and timing of meals in the isolation centres should be improved. Along with the virtual consultations, physical visits of health workers can be increased taking necessary precautions.

Participants experienced different emotions in different stages of disease. Studies done in other countries have shown that patients have negative feelings, including fear, guilt, anger and helplessness.[18,20-22] Different studies showed patients being worried, angry, felt guilty, and restless. They felt loneliness in the initial days of isolation and not being able to spend time with family but were calm in later stage.[18,23] Some of the patients in other studies had suicidal thoughts as a result of long term isolation.[14] Our study did not show such findings, this may be because our study participants did not face long term social isolation. COVID-19 recovered patients in Nepal have admitted that mental health aspect of the isolation is neglected in Nepal.[24] Patients in other studies were angry with their information being leaked in public.[14,22] Such breach of information was not seen in our study. In a similar study conducted in China, patients expressed receiving family and social support which made them feel better similar to our study findings.[23] In a study conducted in China, patients diverted their attention to other things like watching videos, communicating others to make them feel better similar to our study findings.[23] In isolation patients in Butwal along with conducting regular health check-ups of the patients, they were conducting yoga, exercise and dance classes to keep the patients positive and motivated.[16] Hence, psychosocial support from family, friends and health workers is helpful to cope stressful situations. Self coping activities can help to divert attention and help in emotional wellbeing.

Some participants did not feel any kind of discrimination during their stay in isolation centres while others did feel being stigmatized. In a study conducted in Taiwan, patients said that the outsiders used to look with 'fearful eyes' thinking they could infect them which was embarrassing for them.[15] Contrary to our study findings, in a study conducted in China, patients felt stigmatized and discriminated when everyone came highly protected in PPEs when they came to visit.[23] Most of the participants experienced some kind of discrimination in their community. In a study conducted in Hongkong, participants experienced various forms of being shunned, insulted, marginalized, and rejected in the domains of work, interpersonal relationships and use of services similar to our study findings.[25] Similar to our study findings there are accounts of discrimination of neighbours in other parts of Nepal where they demanded eviction of COVID-19 patients from their neighbourhood.[26] Although not seen in our study, there are also some cases where patients in Nepal have received threats in social media, especially after their information was made public in the media.[27] Some of the participants experienced stigma in their office/ workplace from their colleagues. Similar to our

study findings, recovered SARS patients in Hongkong were left alone in workplaces, they were ignored in social activities fearing that other people may be infected by the disease.[28] In other cases, it was so extreme that people were forced to resign from their jobs which is contrary to our study findings.[22] All of us are responsible in preventing stigma and discrimination. With kindness, speaking up against negative stereotypes, sharing individual experiences to provide the support needed by COVID-19 patients, situation can be improved.

The study provides the lived experience of COVID-19 recovered patients from being diagnosed to their recovery. It is a novel study which used qualitative study design to explore the treatment experience, emotional experience, and experience of stigma of COVID-19 recovered people of Banke district. However, being qualitative research, the opinions of the participants may be limited to the participants themselves and may not be representative of other people of the study settings. The relatively younger study population (mean age 36.42) could mean that the same experience might not be felt by people of other age group. During the time when data collection was done, (September- October 2020) the isolation centres were well managed in the district. The findings may be different if data collection was done in other time period. Lastly, complying to COVID-19 prevention protocols, telephone interview was done for data collection which might have impacted quality of information.

CONCLUSION

Patients with COVID-19 had to deal with physical symptoms, emotional turmoil, and stigma. These experiences can be different for different COVID-19 recovered people. Participants felt worried, anxiety, stress, panic, fear, loneliness and, insomniac in different stages of disease. Most of the participants were satisfied by the diagnosis and treatment services they received. However, some complained about cleanliness, quality of meal, and less physical visits of health workers which needs to be improved. Different self coping mechanisms and emotional support from health workers and family members helped COVID-19 patients to recover emotionally. Psychosocial support from family, friends and health workers is helpful to cope stressful situations. Activities like exercise, watching videos, using internet can help to divert attention and help in emotional wellbeing. Our study highlights the need of improving cleanliness and sanitation in the isolation centres, support from health workers through physical visits in isolation centres, and community-based awareness activities focusing on stigma prevention among COVID-19 infected people.

DECLARATIONS

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The study did not receive any funding.

Conflict of interest
The authors declare they have no competing interest.

Ethical approval and consent to participate
Ethical clearance was taken from Institutional Review Committee (IRC), PAHS (Ref: PHP2008131415). Informed verbal consent was taken with each participant before conducting the interview which was recorded.

Authors' contributions
The study was designed by all the authors. The first author collected the data. All authors interpreted and analysed the data. The first author wrote the first draft of the manuscript. It was reviewed by all authors and finalized. The final manuscript was approved by all authors.

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Availability of data and materials
The risk of breaking anonymity is too high to share this data.

Consent for publication
The authors provide consent for publication.

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