Family Caregiver experience of caring COVID-19 patients admitted in COVID hospital of B. P. Koirala Institute of Health Sciences, Nepal

Prekshya Thapa (✉ prekshya.thapa90@gmail.com)
  B.P.Koirala Institute of Health Sciences  https://orcid.org/0000-0002-3049-2427

Sami Lama
  B.P. Koirala Institute of Health Sciences

Gayatri Rai
  B.P. Koirala Institute of Health Sciences

Nidesh Sapkota
  Patan Academy of Health sciences

Nirmala Pradhan
  B.P. Koirala Institute of Health Sciences

Roshni Thapa
  B.P. Koirala Institute of Health Sciences

Pratik Uprety
  B.P. Koirala Institute of Health Sciences

Madhur Basnet
  B.P. Koirala Institute of Health Sciences

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Family Caregiver experience of caring COVID-19 patients

Prekshya Thapa¹*, Sami Lama¹, Gayatri Rai², Nidesh Sapkota³, Nirmala Pradhan¹, Roshni Thapa⁴, Pratik Uprety⁵, Madhur Basnet⁶

¹Department of Psychiatric Nursing, College of nursing, B.P. Koirala Institute of health sciences, Dharan, Nepal
²Hospital Matron, Nursing Service Administration, B.P. Koirala Institute of health sciences, Dharan, Nepal
³Department of Psychiatry, Patan Academy of Health Sciences, Lalitpur, Nepal
⁴Department of Community Health Nursing, College of Nursing, B.P. Koirala Institute of health sciences, Dharan, Nepal
⁵Medical Doctor, B.P. Koirala Institute of health sciences, Dharan, Nepal
⁶Department of Psychiatry, B.P. Koirala Institute of health sciences, Dharan, Nepal

*Corresponding author

Email: prekshya.thapa@bpkihs.edu

¶This author has contributed equally.
Abstract

Background: Informal caregivers played a substantial role in caring the COVID-19 patients during hospitalization in Nepal. This study attempted to understand the family caregiver’s experiences while attending their relatives in a COVID-19 Hospital of Nepal.

Methods: A descriptive phenomenological approach was used to understand the caregiver’s experience of attending and supporting their relatives admitted to COVID-19 hospital of B. P. Koirala Institute of Health Sciences. 13 caregivers of COVID-19 positive were purposively selected from January to March, 2022. Face to face interview was conducted in caregiver residential facility using the interview schedule developed by the department for the purpose of data collection after obtaining ethical clearance from Institutional review committee of B. Koirala Institute of Health Sciences (B.P.K.I.H.S). Data were audio recorded and manually analyzed.

Results: 13 caregivers (6 male and 7 female) participated in the study. The result was summarized under the five domains: Challenges encountered Changes in Physical and Mental Health, Changes in roles and responsibilities, Positive experience and Things that could make Caregiving task easier. The major challenges were financial burden, communication problems, stigmatized attitude, Insecurity and vulnerability, substandard accommodation facility and visitor restriction policy. A wide range of negative emotions as well as unmet physical health needs was reported. Changes in family and occupational roles as a result of caregiving process cause additional stress to the caregivers. Despite all, they tried to positively cope and adapt with the difficult situation and acknowledged the effort of health personnel and other significant members of
family. Provision of essential medical and basic services/facilities within the hospital, reconstruction of open accommodation facility, maintaining proper channel of communication and visitation allowance were suggested as care facilitators to make caregiving task easier.

Conclusions:

This study highlight the role of caregivers is very crucial during the time of health crisis.

Key words: Caregiver, COVID-19, Nepal
Introduction
COVID-19 spread rapidly throughout the world with the dire consequences for low resource countries like Nepal(1). Nepal registered the index case on January 23, 2020 and underwent strict restrictive measures like nationwide lockdown, social distancing and travel restriction after the isolation of the second case on 23rd March(2). Preparedness, readiness, and response status of any country is integral in identifying, managing, and preventing health crisis such as COVID-19 pandemic (3). However, this is not the case with a low income country like Nepal(4). The scarcity of resources such as personal protective equipment, health personnel, infrastructure, and other needed resources tremendously burdened the existing health care services even during last wave of COVID-19(5)(6). Despite the multiple challenges and a fragile health care system, Nepal struggled to manage COVID-19 crisis by increasing free testing at public facilities and free in-patient COVID-19 health services at designated COVID-19 hospitals which was noteworthy. However, the management to contain COVID-19 was not adequate(7)(8).
COVID-19 outbreak created many public mental health concerns and with many possibly unknown dimensions, this disease not only disrupted the lives of COVID-19 patients but also the caregivers caring them (9). Caregiving is a process of undertaking the activities and responsibilities of caregiving which involves different types of support like emotional, physical, and financial support(10). Because of lack of formal type of caregiving in Nepal, major responsibility of caregiving is shouldered by family members who are also referred to as informal caregivers(11). Informal caregivers of Covid 19 had their own COVID-19 exposure risks and concomitant increased concerns about self-care and health. As the patient with signs of severe COVID-19 need to be hospitalized,
caregivers experienced a collection of positive and negative experiences such as stigma, change in relationships, fear of contracting disease, psychological stress, visitation restrictions, economic worries and grieving, which made the caregiving task harder to accomplish(12) (13) (14). Further, several studies established that caregivers faced social isolation, chronic stress psychological distress and physical and mental health problems exacerbated by contagious nature of COVID-19.(15) (16) (17)

This study was conducted during last wave of COVID 19 in a tertiary level hospital, B.P. Koirala Institute of Health Sciences which had 100 bedded COVID-19 hospital and is the referral center in Province1. This institute had a provision for a separate caregiver residential facility for the caregivers of COVID-19 patients admitted to COVID hospital. Despite being only the residential facility in Nepal, this caregiver facility was open shade structure with no separate provision for males and females and had bare minimum facilities. Phenomenology is a philosophical method of inquiry that enables researchers to understand the fundamental structures of experiences and is useful to explore previously unknown and overlooked experiences(18). As this was the only caregiver residential facility in Nepal, it was very crucial to understand the experiences of caregivers which would help to identify specific areas of intervention to offer greater support to the family caregivers during and beyond pandemic. Thus, we used this descriptive phenomenology approach for gaining an in-depth understanding of caregiver experiences and the challenges of informal caregiving to COVID-19 patients during the pandemic.
Materials and Methods

Ethics

Ethical clearance was obtained from the Institutional Review Committee of B. P. Koirala Institute of Health Sciences, Nepal (IRC no. 2176/021). Informed written consent was obtained from each of the participants before enrolling in the study. We followed the consolidated criteria for reporting qualitative research (COREQ)(19) guidelines in this study.

Research Team and Reflexivity:

The research team comprised the multidisciplinary members from hospital, Department of Psychiatric Nursing and Department of Psychiatry, BPKIHS and Department of Psychiatry, Patan Academy of Health sciences, Nepal. The lead author (PT) is a psychiatric nurse who had a prior experience of conducting qualitative studies and did the data collection as well. The data collection process was assisted by (RT), a community nurse and PU, a medical doctor and recorded the interview. The data collection was supervised by GR who was the matron of Hospital and its quality was ensured by the other researchers not working in the hospital (SL and NP). MB, who is a language expert and a psychiatrist was involved in translation of interview guide and oversaw the research design, data analysis and manuscript preparation. Finally NS, who is external to this team, revised the data analysis process. All the research team members were not previously known to the participants.

Study Design: This qualitative study used a descriptive phenomenological approach(20) to understand the family caregivers’ experiences as less is known regarding care experiences related to a newly emerging disease (COVID-19).
**Study Setting**

COVID-19 hospital of B.P. Koirala Institute of Health Sciences was taken as the study site. B.P. Koirala Institute of Health Sciences has 100 bedded COVID hospital and mostly fully occupied during the surge of omicron variant of COVID-19. It is the tertiary referral center in Province 1, and so the cases comprised of heterogeneous sample in terms of caste, ethnicity, age, socio-economic status, ecological regions and other demographic variables.

**Sample Population and Sampling technique**

13 family caregivers of COVID-19 patients admitted in the ward, taking primary responsibility and staying for at least one week at the COVID caregiver residential facility were purposively selected. Sample size estimation was done based on the review of literatures which recommend using typically smaller sample enough to answer the main research questions(21) (22). Sample was taken until when no new information emerged, and the caregiver provided maximum information and data saturation is obtained on the phenomenon. A maximum variation sampling in terms of age, gender, educational levels, occupational status and residential location was used to obtain comprehensive and rich data.(23) The whole study lasted from Oct 2021 to June 2022.

**Data Collection**

The caregiver was contacted by PT who explained the purpose of the study, read out the participant information sheet and obtained the informed consent of participant. After taking written consent for participation in the study, he/she was asked about socio-demographic information and pre-structured open ended questions were asked using interview schedule guide in a separate room nearby COVID hospital maintaining
confidentiality and comfort by the lead investigator herself (PT). Face to face interview was conducted to encourage the participants to discuss their experiences of caring for a patient with COVID-19 using the interview guide developed and validated by the research team for the purpose. The interview guide was piloted on two of the caregivers of COVID-19 patients who were not admitted to COVID hospital and questionnaire modifications were done based on the feedback from pilot testing. Physical distancing and precautionary measures were taken into consideration while conducting the interview. The participants were allowed to express their feeling openly and when necessary probing questions were done to encourage discussions and more clarifications. Each interview lasted 35 to 45 minutes in length which was audio-taped by RT and PU and later on transcribed. Field notes were taken by RT and PU including non-verbal communication. Permission was also obtained to audio record the one-on-one interviews. All interviews were conducted in Nepali, the mother tongue of the participants and the data collector.

Data Analysis

Audio recordings of the interviews were transcribed verbatim in Nepali and later translated into English by the lead researcher PT. Inductive Thematic analysis(24) was done by identifying and reporting the themes generated from the data by familiarizing with the data; coding the data; searching for appropriate themes; reviewing the identified themes and defining/naming the themes. MB and PT coded the data and samples from the transcripts were cross checked by SL. No software was used for the data analysis. The analyzed themes and categories were shared with research team members (GS, NP and NS) for their final review. Final themes were discussed among
the investigators and were then finalized by all investigators. Trustworthiness in the study was maintained as per the criteria proposed by Lincoln and Guba (25). The co-investigator, RT telephoned the participants and reported the findings to ensure whether or not the extracted codes are consistent with their viewpoints. For dependability, the study results was reviewed by a research expert NS who was external to the research team. For conformability, peer check was done by three co-investigators (MB, SL and NP) to ensure the descriptions and categories were accurate. The transferability of data was achieved by maximum variation of the samples, such as different levels of age, education, occupation and family relationship with the patient.
Results:

Table 1: Socio-demographic characteristics of caregivers (n=13)

<table>
<thead>
<tr>
<th>Age</th>
<th>Gender</th>
<th>Occupation</th>
<th>Education status</th>
<th>Home address</th>
<th>Marital Status</th>
<th>Relationship with patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>35</td>
<td>Female</td>
<td>Unemployed</td>
<td>Primary level</td>
<td>Tarahara</td>
<td>Married</td>
<td>Daughter</td>
</tr>
<tr>
<td>26</td>
<td>Female</td>
<td>Agriculture</td>
<td>Secondary level</td>
<td>Dhankuta</td>
<td>Married</td>
<td>Niece</td>
</tr>
<tr>
<td>28</td>
<td>Male</td>
<td>Agriculture</td>
<td>Secondary level</td>
<td>Khotang</td>
<td>Never married</td>
<td>Son</td>
</tr>
<tr>
<td>21</td>
<td>Female</td>
<td>Teacher</td>
<td>Bachelor level</td>
<td>Biratnagar</td>
<td>Never married</td>
<td>Daughter</td>
</tr>
<tr>
<td>37</td>
<td>Female</td>
<td>Homemaker</td>
<td>Primary level</td>
<td>Barahshestra</td>
<td>Married</td>
<td>Daughter-in-law</td>
</tr>
<tr>
<td>35</td>
<td>Female</td>
<td>Self employed</td>
<td>Can read and write only</td>
<td>Dhankuta</td>
<td>Married</td>
<td>Daughter-in-law</td>
</tr>
<tr>
<td>65</td>
<td>Male</td>
<td>Agriculture</td>
<td>Can read and write only</td>
<td>Bhojpur</td>
<td>Married</td>
<td>Father-in-law</td>
</tr>
<tr>
<td>28</td>
<td>Male</td>
<td>Agriculture</td>
<td>Secondary level</td>
<td>Jhumka</td>
<td>Never married</td>
<td>Son</td>
</tr>
<tr>
<td>50</td>
<td>Male</td>
<td>Agriculture</td>
<td>Primary level</td>
<td>Dhankuta</td>
<td>Married</td>
<td>Son</td>
</tr>
<tr>
<td>18</td>
<td>Male</td>
<td>Student, Part time teacher</td>
<td>Bachelor level</td>
<td>Jhapa</td>
<td>Never married</td>
<td>Grandson</td>
</tr>
<tr>
<td>35</td>
<td>Male</td>
<td>Self employed</td>
<td>Secondary level</td>
<td>Inaruwa</td>
<td>Married</td>
<td>Son-in-law</td>
</tr>
<tr>
<td>42</td>
<td>Female</td>
<td>Home maker</td>
<td>Illiterate</td>
<td>Dharan</td>
<td>Married</td>
<td>Wife</td>
</tr>
<tr>
<td>55</td>
<td>Female</td>
<td>Home maker</td>
<td>Illiterate</td>
<td>Chatara</td>
<td>Married</td>
<td>Mother</td>
</tr>
</tbody>
</table>
Qualitative result findings: We summarized our findings and categorized the themes under five domains: Challenges encountered, Changes in Physical and Mental Health needs, Changes in role, relationship and responsibilities, Positive Experience and Things that could make Caregiving Task easier.

1. Domain of inquiry: Challenges encountered

Theme 1: Financial challenges

Almost all the caregivers reported that increased expenses have created difficulties in managing the situation. One of them said that they were not prepared that the expenses would be this high and have to manage by borrowing money. “Now the expenses for staying for 7-10days are likely to be around 70-80. We came with little sum of 10-20 thousand in loan with this much serious patient. We are feeling burden due to financial difficulties.” - IDNO.12. They also expressed that although the treatment inside the COVID hospital is given free of cost, but the cost of medicines and other necessary supplies have to be covered by self. “Although they say the treatment is free, we have to pay the expenses of medicines ourselves”- IDNO1. Another caregiver expressed that some investigations are asked to be done outside the COVID hospital which is very expensive and unaffordable.” They ask for blood tests from the hospital but they ask to do the test outside. They charge a lot when done outside and now our money is finished.” -IDNO 2. The increased financial burden had additionally
hampered those caregivers who had limited source of income and came from remote places. "4-5 lakhs have been already spent including medicines and travels. See, we have limited source of income. In the hills, you cannot sell your land easily, people rather leave. We have to take loans, need to take loans for treatment." IDNO 7

**Theme 2: Communication Challenges**

Another major challenge encountered by most of the caregivers was communication problem such as uncooperative caregivers and unreliable information and improper communication from health personnel. One of the caregivers reported that she felt more difficulty when the other caregivers seem indifferent and less cooperative. “Some friends come but do not inquire about whereabouts, do not speak even when called and do not care anything. It’s difficult when this happens.” –IDNO 2

Some of the caregivers also expressed that they felt the communication from the health personnel to be doubtful and unreliable as they got misinformed regarding patient condition. “Now, it’s like this here- one doctor says one thing and another says other thing. There is one doctor, I do not know his name, who scares us a lot when we ask him about the condition of the patient.” –IDNO 4

**Theme 3: Stigmatized attitude towards COVID**

Stigma, discrimination, neglectful attitude, ignorance and lack of support were also faced by the Covid caregivers. Caregivers expressed that they were less supported and being ignored. Most of the other people fear of being near even to the caregivers and communicated less. “They don’t support you once you get
Covid. Everybody gets scared and run away. They don’t come even when called.” -ID NO2 “Now, this one has got Covid, don’t go near him. That’s what is being done by ignorant ones.”-IDNO 5 One of the caregiver expressed the concerns regarding the final death rituals. He expressed in case of death in the hospital, nobody would even care and they could not perform the rituals. “If died at home, we could do our rituals. If dies in hospital, there’s nothing, we get stigma, discrimination and neglect, people remain away and avoid. Feels like there’s no recognition of the dead person, no care whether it’s death of a person or a dog or a cat.” -IDNO 7”

Theme 4: Insecurity and vulnerability
Female caregivers perceived more stress and vulnerability because of mistrust and fear of unknown male caregivers’ intentions as they had to share the same roof in common in the open shade of the residential facility. One of the caregivers expressed as “What to say, it’s very difficult to stay for female alone. Not all males consider females as their sisters. Sometimes it happens such that I feel terrified. When alone, we have to stay awake whole night. The day before, I was the only female here and could not sleep whole night.”-IDNO2 In contradiction, one of the female caregiver expressed that she felt more secured due to the presence of male caregivers and pointed that it might be more challenging to be the only caregiver as the facility is located nearby jungle area and not well facilitated. “We got courage to stay because there are other males here. Otherwise, there is no facility and it’s really hard for females to stay. And
sometimes when alone, it feels like jungle and feel scary. Feel like unsafe. Cannot stay alone, it’s quite quiet and no much movements.” -IDNO 12

Fear of being theft, looted and other criminal acts due to open space and being in very faraway place were some of the serious concerns of the caregivers. “This place is open like this and feels uncomfortable when alone. It’s difficult to go out leaving behind our luggage and so better to have rooms.” -IDNO 8. “It feels scary to stay alone, the place is quiet. There is not even the sound of people moving around.” -IDNO 11

**Theme 5: Visitor restriction policy**

Most of the caregiver complained that visitor restriction policy made them unassured and uncertain about the patient’s condition inside the hospital. This created doubt, mistrust and confusion on the part of caregivers. “I am not able to see how my mother is staying inside. My evil heart feels doubt if she might be dead, and it’s so if you cannot see. Sometimes I feel like rather taking her home.” -IDNO 1

**Theme 6: Substandard caregiver residential facility and services**

Inadequate basic facilities like restroom, provision of light, water and sanitation were reported by caregivers. They expressed as “there is toilet only and no bathroom and you have to bath in toilet only if you need to.” -IDNO 3, “there’s lock in the toilet but it’s all broken.” -IDNO 6. “The toilet and bathroom is also very dirty. For cleaning, we could also do the cleaning but there is nothing for cleaning.” –IDNO 1 Improper disposal of wastes and mosquitoes during the night would also harm caregiver health and was also reported by caregiver as “And the
wastes get disposed here only, vehicle does not come to collect the wastes. *Because of wastes, mosquitoes are everywhere.*—IDNO 4, Canteen, lab services and drug store being out of premises of the COVID hospital have created additional stress and burden to them were reported by caregivers as- *We don’t get good food here in the Dharmashala. We have to go to the market. Food available in Dharmashala is not good; sometimes the vegetables are not cleaned well.*” “On one hand the medical is far here for all. This is one cause of inconvenience. Other is that there’s problem of drinking water as well here.” IDNO 6.

Another caregiver expressed that because of no light, it is difficult and even scary for them to reach for emergency lab and other services which is distant from the COVD hospital. “*There should have been facility of light but there’s none. Yesterday I had to go to emergency lab at 12:30am and it’s far. Distance is ok but there is no light on the way. See, the way is not that good here and it’s scary if there’s no light.*”- ID No. 13

2. Domain of inquiry: Changes in physical and mental health

Theme 1: Psychological stress, fear, worry, hopelessness and uncertainty

Almost every caregiver expressed feeling of being stressed, burdened and overstretched as a result of caregiving. Caregivers expressed being physically exhausted, drained and stressed as “*There’s a lot of exertion, need to go so far to buy medicines and need to go so far to bring meals for patient, there’s lot of tension. There’s so, so much of tension my god.*” –IDNO5” “*We feel anxious when the patient is more sick.*”- IDNO 2 They expressed the feeling of being
hopeless as “I am hopeless now. I shall bear for treatment as long as my condition and finances allow and then will take home if not able to bear the costs. Now also, I am sustaining on donated money.”–IDNO 1. Fear of contracting virus and uncertainty regarding patient’s condition made them worried about the caregivers. One of the caregivers said “I feel tensed about my mother-in-law’s condition. My husband is not here, he’s abroad and he’s also worried, after all she is his mother who gave him birth. Feel worried if she might not get well. There’s also worry if I might get the Covid myself.”–IDNO 10. It’s scary, feels like if something happens to patient. It’s scary either way.”–IDNO 2.

Theme 2: Unmet physical health needs and physical problems

Almost every caregiver felt that their basic physical needs such as food, sleep and rest were unmet due to exhaustive responsibilities. They expressed that they had to be alert anytime as they could be called from the hospital at any time, which hampered their sleep. “Now, it’s difficult to sleep, they ask for medicine anytime irrespective of night or daytime, and cannot sleep just like that.” -IDNO 1.

Headaches, backaches and fatigue were also reported by caregivers as a result of over exertion and lack of rest. “I am feeling like exhausted with headache, body ache.” – IDNo.11. Because of inadequate facilities near Covid hospital, caregivers had to run here and there for necessary supplies and related investigations making them physically drained and restless. “It’s hustle and bustle for two people, they are calling at night and calling at daytime as well.”-ID No. 1. “You have to go here and there now and then.”-IDNO 7.
3. Domain of inquiry: Changes in Roles and Relationships

Theme 1: Change in personal roles, family responsibilities and guilt feeling

Caregivers reported that they are unable to fulfill family responsibilities as a result of caregiving. One of the caregivers expressed that she was unable to fulfill her role as a mother as “It’s difficult to stay here leaving behind children back at home. One has college in the morning and another has school in the afternoon, so, there’s problem regarding who will prepare the meals. They are eating the meals prepared in the evening next morning as well and that’s a matter of stress.” -IDNO 10

Another caregiver expressed that she felt bad as she could not care for Covid positive mother because of the nature of disease. She expressed as “Yesterday, I was allowed to meet mom. She happened to get out without mask to bask in the sun and I had to move away when she tried to come near me which made me feel very uncomfortable. I could not make her hair and do her dresses sitting beside her. I felt like she had come nearer thinking so but I had to move away. I could not be near mother because of fear of Covid 19 and then I felt somewhat bad.” -IDNO 1

Theme 2: Changes in occupational role

Caregivers also expressed that caregiving role has hampered their work role and had to face financial loss at work. “My business is also in financial loss. There’s loss here and there as well. It would be OK at least if my relative gets well.”

-IDNO 3 My husband was working in the site, now all of sudden; my mother tested covid positive and so had come here leaving his work. IDNo.1
4. Domain of inquiry: Positive experience

Despite the challenges, Covid caregivers also expressed positive experiences such as normalizing Covid-19, adapting and positively coping, appreciating the hospital facilities and services and acknowledging the support from family.

Theme 1: Normalizing and positively adapting with Covid 19

Caregivers normalized the COVID 19 as “After understanding better this time, I felt Covid-19 is not that dangerous thing as well. It’s not that dreadful disease provided we exercise and take care of food. It’s our own weakness to take it that way.” - IDNO 6. Some of the caregivers also expressed being positive even in the difficult situation as there is no other alternative and be positive with whatever they have. “Whatever it be, we should take it in good way, keep laughing and talking.” - IDNO 13. They also expressed that they had somehow adapted to the situation. “Earlier we used to get scared but not now. Now I feel confident like let me face whatever happens.” - IDNO 7

Theme 2: Appreciation of services and support

Caregiver expressed hospital services and care of healthcare providers to be good though it was uncomfortable to stay in caregiving home. They expressed as-“Although there is difficulty in staying here, the way they are taking care of the patients and treating them is satisfactory, it’s good.” - IDNO10. “They have made this facility and so we need not wait outside, need not sit in the sun. We are staying here like a family and it’s fine. We do get some cold but it’s OK. When we have no option, we need to be satisfied with whatever we have.” - IDNO 11” Another caregiver appreciated as they were allowed to visit the patient inside
the hospital and expressed as-“My patient is inside and from today they allowed one visitor to visit inside. We were concerned about the condition inside but saw that our patient is OK inside. We appreciate this.”-IDNO4”. One of the caregiver acknowledged the support from the family and expressed that “I do have my family responsibilities but my husband is helping me in this”. –IDNO 2

5. Domain of inquiry: Things that could and make caregiving task easier

Almost every caregiver expressed the hospital facilities and services need to be improved for making caregiving task easier. They pointed out that maintaining hygiene and sanitation around caregiving is crucial in managing the health and preventing illness. Likewise, proper communication and positive attitude towards caregivers was also expected by caregivers.

Theme 1: Provision of essential services within hospital premises

Most of the caregivers expressed that the emergency lab, medical store, bill counter and canteen facilities should be within the hospital premises. It’s quite far if you need to ask for medicines. It should be near as much as possible”-IDNO 1 “The issue of bringing medicines is that it’s far and it would be better if nearer.”-IDNO 2 “The drug store should be near here.” -IDNO 5 “It would be easier if you own a pharmacy! It would be better if we need not go far to bring medicines and medicines be available here only.” -IDNO 6 “There should be one pharmacy here so that we need not go elsewhere at night. We people from outside might not know the place and might go elsewhere forgetting the way. The facilities should be around here only.” -IDNO 7
Another caregiver expressed that bill counter should be nearby to the hospital and canteen facilities with healthy and affordable services should be managed by hospital. “And let it be so that we need not go that far to the emergency counter to pay the bills.” -IDNO 5 “We need to go far to get meals and feel like it be around here only.”-IDNO8

**Theme 2: Reconstruction and maintenance of facilities to promote safety and comfort**

Caregivers expressed they faced multiple challenges due to open caregiver residential facility. The open facility should be made more secured in order to make caregivers feel comfortable. Caregiver expressed that the existing facilities of hospital needs maintenance and open spaces should be partitioned for safety and comfort of the caregivers. “It would be better if the sleeping place is well organized. This shade is open and needs to be organized. It would be better to have separate rooms with locking doors.” -IDNO 5 Also the existing caregiving home might not be sufficient during the surge of cases. “This facility is ok for the time being but if the Covid cases surge suddenly, this shade is not enough. Better to have one more building. Also, lots of ants come here and it’s better to get plastered.” -IDNO 1”

Maintaining sanitation and hygiene was also importantly felt by caregivers as they expressed as “It would be better if they empty the dustbins daily. Also, it would be better to have separate toilets for ladies and gents.” -IDNO 3”

**Theme 3: Expecting positive attitude and good communication**
Caregivers expected clear communication from health personnel would make them assured regarding patient condition. “Now, when we handover them the meals for our patients (visitors usually give their own meals to their patients although the hospital provides it) they should also tell us clearly whether our dear ones took the meals or not. Sometimes they just say that they did not eat but we should also be told why they did not eat. We cannot have trust if we are not communicated well as we have not seen inside.” -ID NO 4

Caregivers also expected the positive attitude of health personnel towards them would make them feel more better and expressed as “It would be better if we are seen positively when we go there. I wish we are not seen negatively like caregivers of such sick people. I wish doctors see our patients without negligence as we have left our patients in their responsibility and we would be grateful for that if they treat well.” -ID NO 6

**Theme 4: Visitation allowance to support the patients**

Some of the caregivers opined that they should be compulsorily allowed to visit their patient inside the hospital which would make them feel much better. “There should be one to two visitors compulsorily for a patient here. They should be inside nearby the patient. “Patients is in there and we are out here and it’s meaningless this way. Patient would feel comforted if sees her family members and would have high morale. She would also stay there satisfied. We could also ask him what she needs and wants to eat.” –IDNO 7 “My point is at least one person should be allowed to stay with the patient.” -IDNO 5. Some caregivers expressed that visitation of caregiver would even comfort the patient and make
them feel better. "**Whatever it be, we want to go in to see the patient. It’s ok even if allowed once a day. Patients also feel bad if relatives don’t visit. They would feel comfort if we visit.**"-IDNO 6.

**Discussion**

The present study attempted to understand the experiences of caregivers who stayed at COVID caregiver residential facility and supported their relatives during hospitalization period. We summarized our findings and categorized the themes under five domains of inquiry.

Informal caregivers are the major support systems in the Low and Middle Income countries like Nepal(11). Yet, in providing care they face numerous challenges.(26) Our finding revealed several challenges such as financial challenges, communication challenges, stigmatized attitude, insecurity and vulnerability, visitation restriction policy and challenges due to substandard caregiver accommodation facility. One of the major challenges reported by almost every caregiver was financial burden which is consistent with the findings of other studies.(27)(12) This could be because of on and off lockdown situation that created unemployment and job scarcity, particularly for daily wage-based laborers, and vulnerable populations such as disadvantaged and marginalized populations.(28) (29) Moreover, because of caregiving role they might not be able to fulfill their work responsibilities leading to loss of job or no payment for daily wage based workers. In addition to this, the already overstretched and inefficient health care system of Nepal was not prepared to manage the health crisis contributing to increased
Female caregivers felt unsafe and were fearful because of open and common accommodation arrangement in the caregiver accommodation facility. One of the caregivers expressed that "she was unable to sleep whole night as she was only the female caregiver in that place and was scared of male caregivers’ unknown intentions". Moreover, the fear of being robbed, looted or theft added emotional burden to the caregivers. We suggest for the provision of a separate male and female rooms with lock systems in the caregiver accommodation facility for the safety and security of the caregivers. In line with other study findings, caregivers in our study faced stigma, discrimination, neglectful attitude, ignorance and lack of support from relatives, community and even health care personnel. Visitation restriction policy, in addition to the miscommunication from health personnel, led the caregiver to be uncertain and unassured regarding patients’ condition leading to negative emotions such as doubt, mistrust and confusion which is consistent with other studies. Clear communication and adequate information regarding the hospital policies, patient condition and awareness regarding the disease itself is must in preventing many critical misunderstandings, mistrust and collision with the health care personnel and the hospital authorities. Our study findings revealed that the open and common caregiver accommodation facility led to difficulties in even maintaining basic hygiene also greatly contributed to the distress and discomfort of the caregivers besides other things. Almost every caregiver expressed that improper waste disposal, inadequate basic facilities, distant lab services, drug store, canteen facilities added to physical exhaustion and burden.
Another major theme that was derived from the study was changes in physical needs and mental health impact. The physical exhaustion, need to be constantly vigilant (due to common and open accommodation facility as well as uncertainty about the relative’s status), fear of contracting virus, uncertainty, financial burden, unfulfilled roles and responsibilities, stigma and inefficient management led to a large number of negative emotions such as fear, anxiety, helplessness and burnout which have been reported by several other studies as well (33)-(34)(35). Therefore, early psychological intervention is particularly important to caregivers in an epidemic to promote emotional release and mental health could reduce the negative mental health consequences and promote mental health among the caregivers. Another important finding was the burden created due to assuming an added responsibility and adjusting to a new caregiving routine which is consistent to the finding other studies.(36) (37) Female caregivers faced additional difficulties along with caregiving task especially in Nepal, where females are particularly engaged looking after the families and males for income generation activities.(38) Male caregivers expressed that their occupational role was hampered, while the female caregivers were stressed for being unable to fulfill their usual role of mother or daughter. This finding urges to address some of the discriminatory gender norms and roles that negatively impact female caregivers, particularly in the household, to encourage greater sharing of responsibilities among caregivers.(39)

**On the positive note**

This study was conducted during the omicron wave of Covid 19 where the cases spiked in very short duration(40). However, the public were more aware during this phase of
pandemic and thus had somewhat adapted to the difficult situation created by the pandemic. Some of positive experiences were: they had adapted positively with Covid-19 situation and were appreciative of the government and health personnel efforts and existing facilities of the hospital. Caregivers also acknowledged the support from relatives, community and nations which can be taken as silver linings and is consistent as other study findings.(30) (41)

Recommendations from the caregivers

This study has revealed several care facilitators that have implications to address the issues of caregiving during the time of health crisis based on the experiences of caregivers attending the COVID hospital. Provision of basic health facilities as well as essential services like medical stores, bill counter, and canteen facilities would significantly reduce the need to travel here and there, thus decreasing the physical exhaustion and burden. Moreover, caregivers emphasized the need to reconstruct the existing open accommodation facility to separate cabin with lock system for the safety of caregivers. Fear of being rapped, looted, and physically threatened due to open and distant accommodation facility were faced by the caregivers. Therefore, caregiver suggested the provision of safe and secure environment with the basic services within the hospital premises and maintaining sanitation and hygiene around caregiving home for promoting physical and emotional health of caregivers. Caregivers expected positive attitude and clear communication from health personnel which they identified as an area of improvement similar to the findings from other studies(42) (43). Another important suggestion was to allow at least a single visitor once daily to visit their ill relatives inside the COVID hospital. They emphasized that by seeing their relatives, patient would be
more comfortable in ventilating their emotions, and caregiver too will be satisfied by seeing their relatives.

**Conclusion**

This study showed that family caregivers attending the COVID19 hospital and residing in caregiver residential facility faced numerous challenges while attending their relatives. This caregiving challenges hampered their physical health needs and their activity of daily living. Emotional and Psychological issues such as fear, anxiety, and stress were experienced by all the caregivers. Stigma and communication problems further deteriorated the caregiver condition. However, amidst the challenges, caregiver also expressed positive experience of coping and adapting with the difficult situation as well as appreciating the existing facilities of the hospital. Our study revealed several care facilitators such as improving hospital services or facilities, maintaining positive attitude and good communication, visitation allowance to support the patient, and maintaining sanitation around caregiving home which could be instrumental in managing future health crisis.

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Figures

Family caregiver experience of caring patients with COVID-19

- Theme 1: Financial challenges
- Theme 2: Communication challenges
- Theme 3: Stigmatized attitude towards COVID-19
- Theme 4: Insecurity and vulnerability
- Theme 5: Visitor restriction policy
- Theme 6: Substandard caregiver residential facilities and services

- Domain of inquiry: Changes in role and relationships
- Domain of inquiry: Changes in physical and mental health
- Domain of inquiry: Positive experience
- Domain of inquiry: Things that could make caregiving task easier

- Theme 1: Normalizing and positively adapting to COVID-19
- Theme 2: Appreciation of the services and support

Theme 1: Provision of essential services within the hospital premises
Theme 2: Reconstruction and maintenance of facilities to promote safety and comfort
Theme 3: Expecting positive attitude and good communication
Theme 4: Visitation allowance to support the patients

Figure 1

Domains of inquiry and derivation of themes

Supplementary Files
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- S1Table.docx
- S5Appendix.docx