

Understanding the Experiences of Caretakers who Lost their Loved Ones to COVID-19

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ABSTRACT

The purpose of the present study was to understand the experiences of family members who lost their loved ones to COVID-19 in India. Purposive sampling was used to select the participants for the study. The sample was selected from Delhi/NCR and Aligarh. 9 participants took part in the investigation. To gather the data for the study, semi-structured interviews were conducted with participants. 6 themes and 16 sub-themes emerged from the data. The main themes and sub-themes were Hospital (attitude of the doctors, difficulty in getting a bed, lack of resources, regret about taking the patient to the hospital), Loneliness (patient felt lonely at the hospital, loneliness of the caretaker), Support (no support received, support received from immediate family members), Challenges (unusual times, not being able to meet the patient in the final moments, burial, black marketing), Technology (negative effect of social media, use of technology to connect with others), Effect on life (effect on mental health and physical health, grief and coping). The current study gave an understanding of the problems and challenges faced by participants during the first and second wave of COVID-19 in India.

Keywords: COVID-19, India, Family members, Thematic Analysis, Challenges

According to the World Health Organization (n.d.) “Coronavirus disease (COVID-19) is an infectious disease caused by the SARS-CoV-2 virus.” World Health Organization (n.d.) further elaborates that the virus is known to cause respiratory illness in people who are infected. It can lead to a range of symptoms, including cough, fever, difficulty breathing, and fatigue. While the majority of people who contract the virus will experience only mild to moderate symptoms, a small percentage of individuals will become seriously ill and may require hospitalization or other medical interventions.

The first case of COVID-19 in India was reported on 27th January 2020 in Kerala (Andrews et al., 2020). The states that were found to be severely affected by COVID were Maharashtra, Delhi, Gujarat, Madhya Pradesh, Andhra Pradesh, Uttar Pradesh, and West Bengal (Ghosh et al., 2020).

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The situation in India regarding COVID-19 was indeed concerning, and the reasons for the collapse of the healthcare system were multiple. The high population density and the pre-existing weak healthcare infrastructure certainly played an important role, as well as the lack of awareness among masses regarding safety protocols (Patel and Patel., 2022).

COVID-19 was not a normal situation. Usually, during difficult times, people rely on each other's support. But during COVID-19, social distancing made it nearly impossible to meet people in person to share grief. Not only the patients, but COVID-19 took a toll on the family members of those who were affected by it. The loss of a loved one is not easy to deal with. During COVID, meeting your loved ones to seek support was nearly impossible. The lack of resources during the COVID catastrophe, e.g., availability of hospital beds, oxygen cylinders, and proper medical care, also affected the mental and physical health of those taking care of the patients.

Research has found that the spillover effects of disease on family members can be considerable (Wittenberg et al., 2013). Family members' lives can be affected in various ways, including emotional, financial, family relationships, education, work, leisure time, and social activities (Golics et al., 2013). Even those family members who are not caretakers are affected by the illness of a family member (Golics et al., 2013). According to Shah et al. (2021) a person's chronic illness or disability can have a significant impact on the quality of life (QoL) of the entire family, but this critical impact is usually ignored.

METHOD

To the best of researchers' knowledge, this was the first study to understand the experiences of caretakers who lost a family member to COVID-19. The study was conducted to understand the experiences of caretakers who lost a family member during COVID-19 wave in India. Detailed interviews with 9 caretakers (1 from first wave and 8 from second wave) were done using a qualitative approach. We used a constructivism paradigm as a study design. 9 caretakers gave their consent to participate in the study (6 males and 3 females). The mean age of the participants was 36.7 years. Purposeful sampling method was used to recruit participants for this study. The participants were recruited from New Delhi, Noida, Dehradun and Aligarh.

Informed consent was acquired, responses were kept confidential, and participants were given the option to decline taking part in the study. Every other guideline for ethical conduct was laid out by the American Psychological Association (APA) in its seventh edition was followed.

Telephonic interviews were conducted with the participants. Interviews lasted for around 20-25 minutes. The interviews were recorded and transcribed. A few of the questions that constitute the interview schedule were:

- How was your acceptance towards the loss?
- Did social media make the death of your loved one hard to cope?
- Were you able to access health care services, oxygen supplies and other facilities, when you need them?

The objective of the present study was to understand the experiences of the caretakers who lost their loved ones to COVID-19.

Table 1 Characteristics of caretakers in the study

S.no	Gender	Professional status	Relation with the patient	COVID Wave
1	Male	Working	Son	Second
2	Male	Working	Cousin	Second
3	Male	Working	Son	Second
4	Female	Working	Daughter	Second
5	Female	Homemaker	Daughter	Second
6	Male	Working	Son	Second
7	Female	Homemaker	Daughter	Second
8	Male	Working	Son	First
9	Male	Student	Son	Second

RESULTS

Table 2 The analysis of the interviews yielded 6 themes and 16 sub-themes.

S.no	Themes	Sub-themes
1	Hospital	Attitude of the doctors Difficulty in getting a bed Lack of resources Regret about taking their patient to the hospital.
2	Loneliness	Patient felt lonely at the hospital
3	Support	Loneliness of the caretaker No support received Support received from immediate family members
4	Challenges	Unusual times Not being able to meet the patient in the final moments Burial Black marketing
5	Technology	Negative effect of social media Use of technology to connect with others
6	Effect on life	Effect on mental health and physical health Grief and coping

Hospital

The first theme that emerged from the data was Hospital. Most of the caretakers were of the view that their patient didn't receive proper care at the hospital. They mentioned that doctors behaved carelessly with the patients.

"The senior doctors there didn't come to see the patients during that period. The medicines were given by throwing them."

(Participant 1)

"I got her admitted to the hospital. The people there didn't give any medicines to her, her kidney medicine or heart medicine. And for one whole day she didn't get anything to eat."

(Participant 3)

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“COVID and Non-COVID patients were kept in the same ward for quarantine. He got COVID from there.”

(Participant 8)

Participants also reported that they faced difficulty in getting a bed in hospitals for their patient. Due to a large number of COVID patients it was very difficult to get a bed easily in a hospital especially during the second wave of COVID.

“Before getting her admitted in the hospital. I took her to 3-4 hospitals”

(Participant 3)

“The struggle to take her to the hospital and searching a ventilator for her...”

(Participant 4)

“Our family friend spent the whole night searching for the hospital. We got him admitted to a new hospital.”

(Participant 9)

Lack of medical resources was another sub-theme. Caretakers reported that there was a panicking situation because of unavailability or lack of medical resources like oxygen.

“Initially it was a panic phase. It was announced in the hospital that oxygen will run out this evening so, please arrange yourselves.”

(Participant 6)

“We got a bed in a private hospital. The hospital told us we do not have oxygen so I took the concentrator along with me. They admitted us only because we had our concentrator.”

(Participant 7)

“We had to arrange oxygen on our own and that was a very struggling task for us.”

(Participant 7)

“Medical resources were not available (at home) because we didn't have a COVID report. There was no treatment for three days. The doctor was waiting for a COVID report.”

(Participant 8)

Participants also expressed regret in taking their sick family members to the hospital. They believed it would have been much better for their family member to recover if they had remained at home.

“When I met my father for the last time he said “don't take me to the hospital, continue my treatment at home”. He said “you are doing wrong with me”.

(Participant 1)

“We think that we shouldn't take her to the hospital. She was very fearful of that. She was terrified of being alone.”

(Participant 4)

“People were saying don't take her to the hospital.”

(Participant 7)

Loneliness

Caretakers reported that their patients felt a sense of loneliness in the hospital. As they were away from their family members so it was difficult for the patients to manage alone emotionally.

“The day we admitted him in the hospital, he called me and said “take me from here” I made him understand that you will adjust there.”

(Participant 1)

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“Due to lack of oxygen and absence of moral support...he was very sensitive. He felt lonely there, nobody cared for him.”

(Participant 1)

“They made a mole out of mountain of COVID. Nobody was allowed to meet. If people were allowed to meet and if every patient gets social support then it affects the person a lot. If any normal person gets an enclosed room for 24 hours then normal person will become mad. This happened with those who left this world. They didn't get any moral support and it broke them.”

(Participant 1)

“When she sees me, she always asked me to take her home.”

(Participant 3)

She always feared dying alone... My ultimate nightmare was she died in that situation. Nobody was allowed inside the hospital, despite having such a big family.

(Participant 4)

Most of the caretakers in this study also felt loneliness while managing everything on their own. *“My sister was also COVID positive, she was quarantining in Gurgaon. She couldn't see anybody or even my dad. She is the toughest one.”*

(Participant 6)

“My relatives including my uncle and cousin who are on good posts, nobody was there. I was alone, the only family member facing all the hardships alone.”

(Participant 1)

“It was very difficult. There was emptiness when she passed away.”

(Participant 2)

Support

Support was another theme that emerged from the data. Most of the participants experienced a lack of support during the challenging time. In the words of one of the participant,

“We took his body to the graveyard. There were 5-6 people. All relatives are in the same city. There was nobody to console me during my bad time. Only 2-3 friends, doctor friends were there... No support was there. I was alone. No friend, no relative. The situation was like that. There was no one... I was calling all the relatives from graveyard. They are in good positions to come and help me, but nobody came. I had to do everything.”

(Participant 1)

“They came in less numbers. It was kind of an eye wash like people wanted to attend but... the support was available after the death but not before that... I understand, if any such situation comes there would be nobody to manage it, you have to manage.”

(Participant 2)

“I didn't get much support”

(Participant 5)

“I was alone, no social support was available. I had no expectation from anyone. Few people came to meet me.”

(Participant 8)

Some participants were of the view that they received support from their family and friends.

“I said no to all my relatives who wanted to come for the burial but still some of them came.”

(Participant 3)

“Majority of people came in her last rituals. Those who can't attend couldn't find a transport.”

(Participant 4)

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"Friends were supporting me. My maternal uncles are doctors they were guiding me."
(Participant 6)

"Doctors were supporting us... My paternal family supported us a lot."
(Participant 7)

Challenges

Participants believed that first wave and second wave of COVID were challenging times. Many termed it as an exceptional time because of lack of resources, shortage of hospital beds, and lack of support.

"It felt like day of judgement. Everyone was thinking about themselves."

"I have recovered. It was an exemplary situation. It was not a normal situation."
(Participant 2)

"I can't forget that time. I was not aware how the grave was dug, to whom I have to give medical book, I was not aware, how the formalities will be done... There was waiting in the graveyard for the burial. My number came around 12:30 in the night. I gave extra money for the extra labour. I gave rupees 1500 for digging the grave. There was so much waiting (in the graveyard for the burial). That day 21-22 people had died in that area. Nobody was there to help... putting him in the grave because of fearful situation."

(Participant 1)

"I took him directly to the graveyard from the hospital. Doctors told me that his body was in the mortuary. I was going through...I was wearing a PPT kit and mask. Then they allowed me to enter the mortuary and I was opening every icebox there and I was saying no, this is not him. I opened around 15 iceboxes. I can't forget that night."

(Participant 1)

"During the second wave it never looked like that we belong to this world."

"It seem like everybody was dying."

"I was away from my support system. It was most dreadful time of my life. I had never seen anything so bad in my life."

(Participant 4)

Many caretakers regretted on not being able to meet their patient in the final moments. They regretted that their family member passed away alone without meeting them.

"The hospital informed us about his death in the morning. I am not sure at what time he passed away. They came to know when they saw him. But during his last moments no one was there with him."

(Participant 8)

"Her last words literally haunts me like hell she said "I am very sick" I feel very helpless. She desperately wanted me there but I was not there. That helplessness in her voice I could sense that."

"I was depressed and remorseful as she died alone. She might have got worried, wanted to see anyone of us. Everyone has to die. But dying when family is present is a different thing and dying without seeing a family is a different thing. This gives a lot of problem to us and will continue to do so."

(Participant 4)

"His mobile was missing. "What I will do of his mobile, when my father has passed away". I was thinking may be during his last moments, he may have left a message. When he was going, I was not there... (Started crying)"

(Participant 1)

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Difficulty in burial was another issue faced by the participants. Some participants faced difficulty, delay in burial of their deceased family member, others couldn't bury according to proper rituals.

"She (wife of the deceased) wished to see him. The body was not allowed to come home. It went directly to the graveyard from the hospital and we couldn't give him bath. It was not allowed. I feel that I should have given him bath. His body was in a white sack with chains. We put the shroud over the box."

(Participant 1)

"All formalities of burial had taken place."

"We buried him with all the protocols. If we had not done that then we had regretted all our lives. We had taken him to his native place. He was buried in a family graveyard."

"Two weeks before the death of my father my wife's aunt passed away. We were only four people there at time of her burial. We descended her into the grave with a help a cotton sheet and the crane put soil over her grave."

(Participant 8)

Many caretakers also reported black marketing of medical equipment and oxygen cylinders.

"Personally I provided three cylinders. During difficult times, the cylinders were not available. They were available in black. I used to go and stand in a long que for the cylinders. It used to take around 5-6 hours to get them filled."

(Participant 1)

"We brought the cylinder for rupees 52000, we faced black marketing. We had to return the cylinder."

(Participant 7)

Technology

Technology was used to connect with others especially during a burial process. The participants also reported a negative effect of social media during the COVID waves.

"There was negative effect of social media, Facebook and WhatsApp. Every morning when I used to open the apps I came to know somebody has passed away. I stopped seeing FB. I used to get depressed. I lost 25 kgs. Then my friends advised me to look after myself for the sake of my wife and children."

(Participant 1)

"The negative impact of social media was that news of death was coming and people were getting panicked."

(Participant 2)

Effect on life

Caretakers reported a sense of grief and effect on their physical and mental health after the loss of a family member. The caretakers coped while using different coping strategies.

"Binge eating was a coping mechanism, extended family was there"

(Participant 9)

"We were so engrossed in taking care of father that we were not able to grieve for my mother properly. We felt that we didn't get time for my mother."

"I always had a fear for my parents for COVID and that fear was turning into reality so it was very painful for me. I had sleepless nights."

(Participant 7)

"Appetite was low. Lack of interest in work, no interest in going out or use social media. It remained for around 2-3 weeks... I had lot of emotional breakdowns in between"

"It was very difficult to remain emotionally and mentally strong."

(Participant 6)

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“I didn’t pick up the calls of my relatives. People keep asking same thing again and again. That’s why I avoid receiving the calls.”

“I was restless. I don’t have interest in anything but have to do.”

(Participant 5)

DISCUSSION

This qualitative study was conducted to understand the experiences of caretakers who lost their loved one to COVID in India. In-depth interviews with the family members revealed 6 themes and 16 sub-themes.

Hospital was the first theme that emerged from the data. Attitude of the doctors was a crucial sub-theme under this major theme. Most participants reported that doctors had a careless attitude during the COVID-19 wave, especially the second one. The participants also reported difficulties getting a hospital bed, lack of resources, and regret about taking their patient to the hospital. Healthcare was the worst affected sector during the COVID time (Das & Nundy., 2020). Participants also said they felt their patients would have recovered if they had not taken them to the hospital and cared for them at home. Their thoughts were based on the lack of attention shown by the medical staff. COVID-19 has also strained the availability and disbursement of scarce medical resources (Das & Nundy., 2020).

Loneliness emerged as another main theme. The factor of loneliness was significant in older adults who experienced a severe sense of social isolation as a result of interventional measures associated with COVID-19, like quarantine and social distancing that led to adverse effects on mental and physical health (Hwang et al., 2020). Schellekens & van der lee (2020) found that patients and family members reported feeling lonelier than before the pandemic.

Support appeared as another major theme. Many participants acknowledged that they received no support from family and friends. At the same time, few of them reported receiving support from immediate family members that helped them cope with the grief. Research has found that social support is beneficial to adaptation and psychological well-being (Hsu & Tung., 2010). The use of active coping styles and perceived social support act as a protective factor in depression and anxiety (Roohafza et al.,2014). According to the American Psychological Association (2022) people around the world experienced an increase in loneliness.

Challenges during COVID-19 appeared as another theme. The challenges outlined by the participants were unusual times, not being able to meet the patient in the final moments, burial, and black marketing.

It was an unusual time during COVID-19 as many aspects of life were changing (Haines & Berney., 2020). Most of the participants regretted not being able to meet their patients during the final hours. They felt that their family members might have wanted to tell them something before leaving this world, and they regretted that their family member died alone. According to Anderson-Shaw & Zar (2020) the moral conflict and moral distress arising from not being able to do what is right in care providers when they see their family members dying alone can lead to excruciating and continuous grief and despair.

Many participants couldn't get closure because they couldn't bury their dead relatives. Dead bodies were denied a dignified death because of required guidelines specified by countries to contain the COVID-19 pandemic (Kumari, 2023). According to Times of India (2021) around

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70 percent of people paid extra for ambulance services during COVID's second wave and 36 percent of citizens who purchased medical essentials like oxygen cylinders, oxymetres, and concentrators paid more than the market price.

Technology was another theme that emerged from the data. Participants complained that news and sharing on social media had affected them negatively. But there was also a positive side to technology. Few participants used technology to connect with other family members and friends, e.g. they used Zoom during burial so that other family members could also get a sort of closure (by seeing their relative getting buried). Ahmad & Murad (2020) had found a role of social media in spreading anxiety during COVID-19 in Iran. On the other hand, social media usage was also found to affect psychological outcomes positively through social support (Cho et al., 2023).

COVID-19 was also found to affect family members. Research has found that economic difficulties, job loss, deteriorating mental health, illness impacted families, sleep problems, and poor dietary behaviour habits (Gayatri and Puspitasari., 2022; Ding et al., 2022).

Majid et al. (2022) found that grief was more common in males and in relatives whose loved ones died of COVID-19. People mostly adopted avoidant coping strategies whose relatives died of COVID-19. It was difficult for individuals to grieve the loss as most of the mourning was done in isolation, with little to no support available. Most participants could not perform the final rituals, which complicated their grieving process.

The limitation of the present study is a small sample size. Still, the current study emphasizes the importance of taking into account the challenges faced by the family members who lost their relatives to COVID-19. This study brought into the limelight the challenges faced by family members, and it paves the way for follow-up studies to study in depth all sorts of repercussions on carers of the patients and devise suitable measures to bring them out of the psychological consequences of the trauma.

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