

# Marginalized COVID-19 patients and their significant others in Kashmir (India): manifesting the hidden structural vulnerabilities

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## Summary

Using a qualitative approach, this study aimed to undertake an in-depth exploration of the experiences of COVID-19 patients and their significant others among the economically weaker sections in Kashmir. The study was conducted on 18 participants of different households solely from rural Kashmir while using the purposive sampling technique to recruit the participants and the principle of data saturation to determine the sample size. Data were collected using semi-structured in-depth interviews and analyzed through Braun and Clarke's thematic analysis framework. From the data analysis, six overarching themes of diagnosis, healthcare, treatment, survival thereof, social support and stigma were arrived at, which delineated the direct or indirect experiences of participants with COVID-19. The findings of the study revealed that the economically weaker sections of rural Kashmir are deprived of requisite healthcare facilities, which further intensifies their vulnerabilities to COVID-19 and associated health issues. They lie at the core of acute health disadvantage amid the COVID-19 crisis, and are hence drifted toward extreme marginality and socioeconomic adversity.

**Keywords:** COVID-19, marginalization, healthcare, social support, stigma

## INTRODUCTION

Since the declaration of COVID-19, first as a Public Health Emergency of International Concern (PHEIC) on 30 January 2020 and subsequently the pandemic on 11 March 2020 (WHO, 2020), it has taken a quantum leap in geometric progression throughout the globe, with 35 305 82 confirmed deaths and 169 597 415 cases as of 31 May 2021 (WHO, 2021). COVID-19 of its own is non-discriminatory (Chen *et al.*, 2021), affecting people right across the board, with some sections of the populace being comparatively more susceptible to it. So, apart from being biological in nature, COVID-19 could well be viewed as a biographical event in the lives of people, by radically disrupting the structure of their everyday life and compelling them to respond to the changing circumstances. It has affected different groups differently, depending on the place they live, the quality of information they possess about

the disease, the skill to utilize information content in action, media accessibility, schooling, cultural differences and the availability of healthcare programs and actions (Oliveira *et al.*, 2021).

COVID-19 is provoking uncertainty, widening the prior inequalities and orchestrating stigmatization and discrimination among all the infected and their significant others (spouses, parents, children and siblings), in general, and those of the marginalized in particular. Disease, pain and public stigma suffered by an individual also affect the life circumstances, social acceptance and psychological health of significant others (Jafree *et al.*, 2020). This is because health and illness are a family affair (Wright and Bell, 2009), which is manifested in the full spectrum and scale of the current COVID-19 pandemic (Ones, 2020). Studies have shown that serious illness and life challenges impact the family unit, and reciprocally, the functioning of the family unit influences the health and well-being

of each family member (Wright and Leahey, 2013). However, the intensity with which an individual and her/his significant others are hit by any serious illness is vested in the historic and persistent social, economic and educational vulnerabilities among the families. Usually, the households with better socioeconomic capital can afford the best possible healthcare and isolation facilities to ensure the effective treatment of their members infected with COVID-19. However, the poor and marginalized are prone to be hit the hardest on being declared as COVID-19 positive. The vulnerable communities with deeply entrenched poverty, overcrowded housing, limited employment flexibility (Fisher *et al.*, 2020), homelessness, disability, and the aged face greater immediate risk of COVID-19 (The Lancet COVID-19 Commission, 2020) and may also experience inappropriate or delayed treatment. Studies suggest that there are inequitable consequences of the COVID-19 pandemic for low-income families (Chen *et al.*, 2021), migrant workers and racial and ethnic minorities (The Lancet, 2020), and it may cause particular harm to them because they possess lower academic and socio-emotional skills as against the rich or highly educated (Attanasio *et al.*, 2020). So, the impact of social disruption, caused by COVID-19 needs to be considered in the context of pre-existing vulnerabilities in families, including racism and marginalization, economic hardship or history of adversity (Prime *et al.*, 2020). Globally, the response to COVID-19 has centered on hospital services, enhancing the availability of intensive care unit (ICU) beds and ventilators (Medina *et al.*, 2020). However, India's healthcare system faces an acute shortage of infrastructure even in normal circumstances (Seervai and Shah, 2021), and this pandemic has further stressed it thereby creating an imbalance between the demand and the availability of care.

## COVID-19 IN KASHMIR

The Union Territory (UT) of Jammu and Kashmir (J&K) has battled with the second wave of the COVID-19 pandemic since March 2021 and has recorded 3870 COVID fatalities and 285 070 confirmed cases as of 31 May 2021 (Akmali, 2021). As per health experts, the second wave of the COVID-19 pandemic in Kashmir proved to be more gruesome than its first wave. It left a deathly trail as April registered 45 123 infections and 289 fatalities, while more than 72 000 COVID-positive cases and 963 deaths were recorded in the first 18 days of May across J&K (Wani, 2021). It has overburdened the healthcare facilities and medical professionals in the region. The Doctors Association Kashmir (DAK) on 28 April 2021 claimed that the hospitals in Kashmir were running out of beds and ventilator support, risking

the lives of critical patients. The government of J&K imposed a strict lockdown in 11 of its districts on 29 April 2021, and on the first day of lockdown, 3532 positive cases were reported, and soon in a week, the daily new cases jumped to around 5000. The exponential surge in daily infections and deaths led to the subsequent extension of lockdown to the whole UT of J&K.

## AIM

The current study has been carried out to undertake an in-depth exploration of the experiences of COVID-19 patients and their significant others among the economically weaker sections in Kashmir. It attempted to highlight the response of the rural poor to COVID-19 and the plethora of challenges associated with the fact of being poor and positive with COVID-19.

## METHODOLOGICAL STANCE

### Approach and the selection of participants

A qualitative research approach has been employed to understand the participants' perceptions, in the pursuit of gaining a comprehensive understanding of the context under investigation. The study was conducted in rural areas of Kashmir, primarily, due to their impoverished healthcare systems. Prior to sampling, the contact details of COVID-19 patients, survivors and their significant others were collected both from the Block Medical Officers (who supervised the COVID-19 testing) and through personal contacts. At the outset, 46 potential individuals were contacted, however, only 33 agreed to participate. The purposive sampling technique has been employed to recruit the participants. Given the fact that in purposive sampling, the researcher's judgment is central in selecting information-rich and context-relevant cases, participants, as such, were recruited by adopting the following criteria:

- (a) suffering/recovered from COVID-19 since its second wave in Kashmir or being her/his significant other (family);
- (b) belonging to below poverty line (BPL);
- (c) a resident of rural Kashmir and
- (d) willing to participate in the study.

Data collection was grounded in the principle of data saturation. The participants were recruited one after the other until no new relevant information surfaced. After 15 interviews, data saturation occurred. To avoid any information from getting left out, three more participants were recruited and interviewed extending the total sample size to 18 (Table 1).

**Table 1:** Details of participants

No.	Sex	Who is/was infected?	Place of treatment	Status of illness at data collection	Age at infection
1	Female	Mother	Hospital	Undergoing treatment	82
2	Male	Self	Home	Undergoing treatment	85
3	Female	Self	Hospital	Undergoing treatment	82
4	Male	Self	Home	Recovered	39
5	Female	Brother	house of relatives	Recovered	29
6	Male	Mother	Home	Undergoing treatment	62
7	Male	Self	Hospital	Recovered	34
8	Male	Self	Home	Recovered	35
9	Male	Self	Home	Recovered	40
10	Male	Self	Home	Recovered	51
11	Female	Spouse	Home	Recovered	40
12	Female	Father	Hospital	Died	48
13	Female	Son	Home	Recovered	32
14	Female	Self	Home	Undergoing treatment	43
15	Male	Self	Home	Recovered	30
16	Male	Father	Hospital	Died	60
17	Female	Father	Hospital	Undergoing treatment	57
18	Male	Self	Hospital	Undergoing treatment	41

Source: Fieldwork.

## Procedure and analysis

Semi-structured in-depth interviews were conducted with all the 18 participants, who belonged to 18 different households of whom six COVID-19 survivors and six significant others of the infected persons were interviewed at their respective homes while following all the Standard Operating Procedures (SOPs) in vogue. However, with the two coronavirus patients undergoing treatment at hospitals, two attendants and two patients in home isolation, telephonic interviews were conducted at their convenient times. Interviews were conducted in the local Kashmiri language from 15 April 2021 to 31 May 2021, a period predominantly influenced by the second wave of the COVID-19 pandemic in Kashmir. Given the purpose of the study, a semi-structured interview schedule was devised by the researchers for data collection. To avoid the complicity and presumptions of the researchers, the questions included were largely open-ended and free from technical terms. With the permission of participants, all interview sessions (which ranged from 45 to 75 min) were audio recorded.

The data were analyzed using Braun and Clarke's (Braun and Clarke, 2006) thematic analysis framework which included data familiarity, generating initial codes to organize data, identifying primary themes, evaluating themes, labeling identified themes and reporting results. During each phase of thematic

analysis, we followed the trustworthiness criteria outlined by Lincoln and Guba (Lincoln and Guba, 1985) to establish rigor in qualitative research. The identity of the participants has been kept anonymous. Instead, numbers or pseudonyms have been used while presenting their narratives to ensure confidentiality.

## RESULTS AND DISCUSSION

From the data analysis, six overarching themes delineating the direct or indirect experiences of participants with COVID-19 were recognized.

### Diagnosis

Being highly contagious, the cause, diagnosis and treatment of COVID-19 lie, primarily, in the awareness of issues related to it. Unawareness regarding COVID-19 enhances the apprehensions of people to get tested.

### Awareness

During the COVID-19 pandemic, in addition to the interventions of physical distancing and lockdown, timely access to knowledge and public awareness on prevention methods can be the difference between life and death (Wolka *et al.*, 2020). In our study, we found that the rural poor possess very little or no knowledge of COVID-19 and allied symptoms, mostly due to their illiteracy and less exposure to mass media

which disseminates health information rapidly among the masses in contemporary times. Many participants revealed that they visited hospitals for health issues, other than the COVID-19 with no apprehensions of being affected by it. An old-aged COVID-19 survivor described that he was taken to hospital for a health issue which has no link with coronavirus, but got diagnosed with it on getting tested. ‘I suffered a severe prostate problem, and for that purpose only, my son took me to hospital. As per hospital norms, my COVID-19 test was conducted which came positive. It put me in a deep shock, as I used to consider myself normal. I never thought of being infected with it’ (P2). Unawareness regarding COVID-19 can turn out to be dreadful for the patients and their significant others. A participant revealed, ‘My mother got sick, but we took it lightly and got some medicines for her from a local medical practitioner. Gradually, her health deteriorated, and then only we took her to the hospital where doctors declared her COVID-19 positive and admitted her for being critical. It shocked us all. Our ignorance led to a huge delay in her treatment, compounding her health complexities’ (P6). In this case, timely treatment would have been effective, but due to the lack of awareness regarding COVID-19, her family failed to do so. It risked her life along with her family members, who used to stay with her while being unaware of her infection.

### *Apprehensions*

Public health experts argue that the stigma associated with COVID-19 is creating fear among the masses and acts as a deterrent to the effective management of the disease (Bhattacharya *et al.*, 2020). Moreover, the fear of self-isolation or hospitalization and significant loss of income or job subsequently added to the reluctance among people to get tested for coronavirus. However, testing is a fundamental tool facilitating the early detection and treatment of one’s infection. People hardly reveal the symptoms of COVID-19, due to the fear of facing social boycott, and discrimination, leading to low testing, increased mortality and higher chances of community transmission. Test avoidance as we found, has emerged as a growing problem, especially, in the rural areas of Kashmir, where people lack basic awareness regarding the contagion. A participant described that two of his friends had apparent symptoms, but still, they concealed them to avoid discrimination. ‘I along with two of my friends had similar symptoms. Both of them refused to get tested because of their apprehensions of testing positive. They were scared of society’s discriminatory attitude towards such patients. For them, testing positive makes the infected live like “untouchables” in society. However, I tested positive and followed the medical advice accordingly’ (P15).

To contain the infection, hospitals, in Kashmir, have made it mandatory to conduct COVID-19 tests on all patients seeking medical care. However, it has simultaneously increased the apprehensions among people about getting diagnosed with coronavirus. So, those who feel unwell or experience symptoms hardly prefer to visit the hospitals, to avoid the risk of getting declared COVID-19 positive. A girl participant proclaimed, ‘my father felt ill and had moderate symptoms. He refused to visit the hospital and instead purchased some medicines from a local medicate. Afterward, his health deteriorated all of a sudden. We rushed him to the hospital, where doctors diagnosed him with COVID-19, and finally lost the battle of his life. We mourn his delayed diagnosis, more than his death’ (P12).

The apprehension of testing positive for COVID-19 is also associated with losing precarious work, especially among the poor and marginalized sections. For lower-income households, a 14-day quarantine or self-isolation of the main breadwinner could lead to a significant loss of their income and may add to their vulnerabilities. A participant revealed, ‘On noticing mild symptoms, I decided not to seek medical assistance while presuming that testing positive may end up losing my job of teaching at the local tuition center. Not only this, the whole center will get sealed and I will be blamed for it. So, I concealed my symptoms. Only after facing acute breathlessness, I went to the hospital, where I got diagnosed with COVID-19’ (P4).

### *Healthcare*

Healthcare is the diagnosis, treatment and prevention of disease, illness or other physical and mental impairments in human beings. Accessibility and the presence of the capital determine the quality of care, an individual can avail.

### *Accessibility*

Access to healthcare refers to the ease with which individuals can obtain the needed healthcare, and the level of access influences the use of medical services and the health status of the population (Núñez *et al.*, 2021). It is inevitable for overall physical and mental health status, diagnosis and treatment of diseases and the quality of human life. However, India’s rural healthcare remains inadequate to tackle the challenges posed by the COVID-19 pandemic, especially in northern India, due to the shortage of doctors, hospital beds and necessary equipment (Mitra, 2020), apart from the paucity of testing services, weak surveillance system and poor medical care, making the pandemic to create a special challenge (Kumar *et al.*, 2020). The rural residents encounter stern barriers in accessing healthcare that limits their ability to obtain the care they need. In our study, it became evident that the people living in rural

areas of Kashmir need to travel to the hospitals and seek medical care for COVID-19. However, transporting the sick to hospitals during lockdown is the foremost challenge, which the rural poor face. This is because they utterly depend on public transport to move from one place to another and are devoid of personal transportation, which altogether limits their access to COVID-19 wards, amid lockdown. Despite apparent health complications, they avoid visiting the hospitals or else need to pay an unaffordable hefty amount to hire private vehicles for carrying the patients to hospitals. A participant along with his ailing mother had to wait for hours on road, after leaving his home to reach the hospital. He revealed, 'public transport service was unavailable and only a few private vehicles were noticed on the road, but no one carried us. Even though the hospital is just 5 kilometers away from our village, the non-availability of transport made it inaccessible. Feeling disappointed, I went to a local cab owner who initially denied transporting us but later agreed against a hefty fare. Then only, I was able to admit my ailing mother in the hospital where she was diagnosed with COVID-19' (P6). Due to COVID-19, the public healthcare (PHC) in India has got overburdened and in this context private hospitals can conveniently fill the growing void to meet the demand for care. However, due to their exorbitant costs, poor people are unable to avail such services. A COVID-19 survivor, who desired to get his health issues treated at a private hospital, could not make it happen. 'On noticing mild symptoms, I went to a private hospital. Shockingly, I was asked to pay four thousand rupees for a COVID-19 test, which was beyond my capacity to pay, rendering me disenchanted' (P4).

### Medication

The role of medical care is significant for people with chronic illnesses and is particularly relevant in the COVID-19 crisis, where many people have concerns related to medicines (Kretchy *et al.*, 2021). The COVID-19 patients require optimal adherence to prescribed medications, to ensure better immunity, viral suppression and effective treatment. However, the economic crises, stemming from the effects of catching coronavirus makes the poor, experience hardships in arranging medicines, a balanced diet, and disposable items, to deal with the disease. A participant described that once her husband tested positive for COVID-19, he lost his job, and they had no money for his medication. 'My husband was apprehensive to buy medicines, with no money in hand. I purchased the required medicines for him on debit. We were told to offer him food in disposable ware to ensure others' safety but due to financial constraints we failed to do so' (P11). Another woman whose son, the main breadwinner of the family

got infected with COVID-19 recounted, 'I am a widow. My son was working as a private tutor. He used to spend his earnings on household affairs. Since he tested positive, his income got halted. We were hardly able to buy medicines for him on prior savings. We couldn't even offer him a balanced diet as suggested by the doctor. That era of desperation even today continues to haunt us' (P13).

### Treatment

Treatment of the COVID-19 depends upon the signs and symptoms of the patients. Some patients show mild or severe symptoms while as many show no symptoms at all. Depending upon the nature of symptoms, the patients are advised for quarantine, self-isolation or hospitalization.

### Quarantine and self-isolation

Due to the overburdening of public health infrastructure in Kashmir, the asymptomatic patients of COVID-19, and those with mild symptoms have been advised to undergo home isolation, instead of getting admitted to hospitals. The guidelines issued by the Ministry of Health and Family Welfare, Government of India (2021) recommended that such cases should have the requisite facility at their residence for self-isolation and for quarantining the family contacts. In practice, the guidelines concerning self-isolation are not inclusive and had ignored the plight of homeless and marginalized sections. They usually dwell in substandard houses and are deprived of adequate infrastructure, required to isolate their infected family members. In such housing conditions, the significant others of the COVID-19 patients are at heightened risk of contracting the virus, primarily due to its lethal communicability. Participants described the insufficient availability of rooms and unhygienic conditions within their households as troublesome for the whole family. A participant, whose mother had contracted the COVID-19 narrated, 'I along with my three children, spouse, and parents have only one bedroom, a kitchen, and a common washroom to survive. Earlier my father was infected with COVID-19, and now my mother is battling it. She undergoes self-isolation in the bedroom, since after getting discharged from the hospital. All the other family members eat, stay and sleep in the small kitchen we possess. You have no idea how crucial it is to survive in such congestion. I fear we all may get infected. This thought makes me restless and I feel estranged' (P6). Arranging home isolation is one of the greatest challenges associated with being COVID-19 positive among the poor and marginalized families in Kashmir. A girl participant recounted, 'when my brother tested positive, our whole family got plunged into utter despair for being unable to offer him a separate room for self-isolation.



We have only one room and a small kitchen to live in. Close relatives abandoned us. My mother helplessly approached one of our relatives, who live in another district. They agreed to offer a room to my ailing brother, and we shifted him there. However, leaving a sibling in isolation at a far-off place, and that too when he needs our care the most is undoubtedly traumatic and full of uncertainties' (P5). Another participant narrated, 'our house is too old. Half of it is owned by us, and the other half belongs to my uncle. After testing positive, I isolated myself in the room that I used to share with my spouse and child. Our house lacks wash-room facilities, and hence, I have to move outside. I preferred odd times for it so that no one could see me, to avoid blame. Lack of facilities curbed my freedom and I felt like caged' (P8). A woman who underwent self-isolation at home said that the scarcity of rooms made her whole family suffer. 'I along with my spouse and two daughters possess a single room to live in. My husband had symptoms, but he couldn't adopt proper isolation. Gradually, we all developed symptoms, due to congestion. Except for one of our daughters, the whole family tested positive for COVID-19' (P14).

### *Admission to the hospitals*

During the second wave of the COVID-19 pandemic in Kashmir, only those coronavirus patients who are serious, and need critical care are being admitted to hospitals. However, with the massive spike in daily cases, the PHC system is witnessing an influx of patients, which drastically increases the risk of infection and improper care within these hospitals. Participants expressed dissatisfaction over the unsatisfactory conditions and lack of proper facilities at public hospitals. A participant who serves as an attendant to her ailing mother in one of the state-run hospitals narrated, 'My mother is admitted for COVID-19 in hospital. I am sitting next to her bed, due to the shortage of space. I wear a PPE kit, but still fear getting infected, due to congestion. New COVID-19 patients are being allowed, even when the Covid ward is already overcrowded. It risks the lives of other patients and attendants. Her health is better now, but overcrowding and mismanagement increase her chances of re-infection' (P1). Another participant described, 'the hospital where my father is undergoing COVID-19 treatment is far from our home. Hospital management offers him food, but I have nothing to eat. Food outlets outside the hospital are all closed due to lockdown. Lending food from home is also impossible, as we have no transport facility' (P17).

### *Survival thereof*

The shutdown of almost all economic activities in the wake of the COVID-19 pandemic is likely to give rise to a financial crisis and an increased poverty

rate, impacting the livelihood of citizens (Summerton, 2020). The COVID-19 pandemic and resultant lockdown brought with it an unprecedented economic disaster, affecting adversely the survival of the rural poor in Kashmir. On testing positive for COVID-19, they lie at the risk of job loss, poverty or indebtedness.

### *Job/work loss*

The economically weaker sections that generally rely on daily wages face grim job prospects as the consequent lockdowns have crippled the whole economic structure of Kashmir. Their economic vulnerability gets further intensified when any of their family members, especially the earning head gets diagnosed with COVID-19. It makes the infected, and their family members witness tough survival, through the entire course of their recovery and beyond, thereby drastically affecting their biographies. A participant, after catching coronavirus, recounted his encounter with it as a biographically disruptive event. 'I was working in a joinery mill, with three more carpenters there. Only I tested positive for coronavirus, and the whole production unit came to a standstill. Though others at the workplace tested negative, still couldn't resume work due to restrictions. We all lost our livelihoods, and our daily life got severely altered' (P9). After getting infected with COVID-19, both the patients and their significant others among the marginalized communities are destined to face economic adversity and experience difficulties in managing their daily affairs. A girl participant desperately stated, 'our father had died a decade ago. To supplement the family income, I along with my brother was providing tuition to students at our home. Once my brother tested positive, their parents refused to send them for further tuition. Students were having smartphones but were still denied to attend virtual classes. Even they refused to pay the pending installments. We completely lost our livelihood, which added to our miseries. Now, my brother stands recovered, but we have no student to teach at all' (P5).

### *Poverty and indebtedness*

Getting infected with COVID-19 intensifies the economic adversity of the marginalized sections. They encounter constraints in arranging food and medication and are hence bound to borrow money from others, which alleviates their poverty and pushes them to debt. A COVID-19 survivor lamented, 'once I tested positive with COVID-19, I couldn't work further. My earnings got halted, and I had meager savings, which I spent on family in the initial days of my self-isolation. Afterward, I purchased the necessary household items on debit. Now, I am drenched, both in debt and poverty' (P9). Another participant shared his experience of how getting infected with COVID-19 made

him lose his livelihood. 'I was running a garment shop in town, which got closed due to lockdown. I was opening it in the late evenings, to dispatch items to my customers. Also, I was selling at my home to earn for survival. But, on testing positive, people left purchasing from me. Now, I am recovered, but unable to overcome the debit of traders' (P8). Another participant added, 'I used to work as a travel guide for tourists. Due to lockdown, I lost my job. My father got infected with COVID-19, and I utilized all my savings on his treatment. He died, and our family had no money to pay for his shroud and burial. Finally, I approached a Non-governmental organization (NGO) that helped me out' (P16).

### Social support

Social support is the tangible or intangible assistance or help that egos obtain from their social networks, to deal with life's vicissitudes. Social support can be categorized into emotional support, instrumental support, informational support or appraisal support (House, 1981). Adequate support from family, close friends, colleagues or healthcare workers can help patients improve sleep quality and ameliorate their distress, thus helping them reduce their negative emotions during the pandemic. The COVID-19 patients receive or expect social support, both from their kin and non-kin groups, apart from medical professionals and NGOs.

### Kin-based support

Within kinship, it is only the family unit that serves as the chief support system for COVID-19 patients. It is due to the fear of catching coronavirus, that even the relatives stop visiting the patients to assist them. All COVID-19 patients in our study received due support, and care from their significant others, throughout the entire course of their isolation and treatment. A COVID survivor described his family's support as pivotal during his encounter with the disease. 'Testing positive alleviated my fear and anxiety. However, my family treated me with the utmost care during my isolation at home. I would not have been able to manage the disease, and get well without their support. They encouraged me to fight the infection instead of surrendering to it' (P15).

Some participants narrated that daughters have been a great source of support for both the infected as well as for her/his significant others. An elderly mother described how her daughter became a source of solace for her. 'I am in bed at the hospital for the treatment of COVID-19. My sons have to take care of their families, so they left. My daughter came from her in-laws and is now sitting next to me in the Covid ward. She is very supportive and caring. With her, I feel comfortable' (P3).

### Support of peers and neighbors

Quite often, the COVID-19 patients and their significant others suffer from a lack of support, on the part of non-kin groups, including friends, colleagues and neighbors, which exacerbates their psychological problems. This is mostly due to the highly contagious nature of the COVID-19, restrictions on movement, emphasis on physical distancing and stigma associated with the disease, thereby triggering social isolation among the patients. This notion of biographical disruption associated with COVID-19 gets illustrated from the narrative of a participant who never expected to be alone in hard times but, got excluded soon after catching coronavirus. 'I opted for self-isolation at home. Little did I know that I and my whole family would be shunned by all. People stopped talking to us and purchasing goods from my grocery shop, which my father used to run during my illness. It hampered our earnings and made us suffer badly' (P15).

The empathy and sharing of information by COVID-19 survivors with those suffering from infection has been found to perform a significant role in eliminating fear from the sick. A participant described, 'after testing positive, I lost all my hope to survive. I used to cry a lot. Everybody except a coronavirus survivor of my village seemed careless. He visited my home and shared his personal experience of the disease with me. He made me understand that recovery is possible. I got encouraged otherwise I was feeling so scared and lost' (P10).

The interaction of COVID-19 patients with one another also served as a source of support for them. A COVID-19 survivor held that 'everybody left us once I tested positive. Even close friends, neighbors, and relatives other than my family never called to know even if I was alive. So, I used to talk with other three COVID-19 patients regularly over the phone to feel relaxed' (P9).

### Institutional support

The Government of India responded to the COVID-19 crisis by announcing several social protection schemes, such as direct benefit transfers, free LPG refills, grains and pulses for the poor (Bansal, 2020), but these benefits were not availed by all of them due to implementation failures (Johri *et al.*, 2021). Many of the participants in our study were unaware of these entitlements while others showed a sense of dissatisfaction. A participant who was associated with Mahatma Gandhi National Rural Employment Guarantee Act (MNREGA) as a worker narrated, 'during my treatment at the hospital, I heard that some amount of money has been transferred to the bank accounts of poor workers. However, the banks were closed due to lockdown, so we failed

to collect the same on time. Also, I don't know about ATM services' (P7).

Knowledge regarding the management of COVID-19 is pivotal in ensuring positive results among the patients undergoing self-isolation at their respective homes. Lack of proper information about the disease may put their family members at risk. Participants in our study who had undergone self-isolation described the lack of support and information sharing on the part of hospital administration. They felt helpless in how to manage the infection and protect their loved ones. A COVID-19 survivor narrated, 'during my self-isolation at home, the concerned medical professionals never tried to know about my health status. Even they never shared any information regarding prevention with me, which added to our uncertainties' (P10). Another participant revealed that the hospital staff neither checked his health status nor provided him with the kit required for self-isolation. 'They asked me to go for self-isolation and promised that a medical kit will be sent to my home. I am recovered now but am yet to receive it' (P8). Participants further described that instead of assisting them, the hospital staff made their COVID details public on their website, adding to their problems. A participant narrated that he was stigmatized once people came to know about his illness on social media. 'On testing positive, I went for self-isolation anonymously. However, the list of individuals, who tested positive that day, was uploaded on the hospital's website. People shared the list in local WhatsApp groups, and we all became the targets. It would have been fine if they had only published the names, but giving addresses, and contact numbers served as an invitation of trouble for us' (P4).

Many participants in our study applauded the role of NGOs in dealing with COVID-19. A patient who underwent treatment at the hospital said, 'I am ill and hence unable to earn. Other family members at home are also infected with COVID-19. Days ago they were having no food to eat. They approached a local NGO that provided them food, sufficient for a month' (P18). Another participant said, 'my father had to suffer because of acute oxygen shortage at the hospital. I approached an NGO who provided us with an oxygen cylinder thereby made my ailing father breathe' (P16).

## Stigma

Pandemics of contagious disease outbreaks have historically been plagued by stigma, an attribute that diminishes the social image of an individual. Erving Goffman theorized that social stigma is an attribute or behavior that socially discredits an individual, who effectively gets branded as the 'undesirable other' by society. The stigma associated with diseases and illness often gets manifested in the form of othering, prejudice,

discrimination or stereotyping. Mary Mallon an Irish immigrant who worked as a cook in New York was suspected of spreading typhoid in the early 20th century and became infamous as 'Typhoid Mary' (Leavitt, 1996). AIDS has been termed the 'Gay Plague' and divine punishment for homosexuality (Van Wyngaard, 2006). Likewise, the COVID-19 since its origin in Wuhan China has been termed as 'Chinese Virus' or 'Kung Flu' (Bhattacharya et al., 2020).

### *Pre-recovery stigma*

COVID-19 evoked blatant stigma and discriminatory behavior toward those individuals, who are perceived to have any contact with the disease (Bhattacharya et al., 2020). In our study, we found that the COVID-19 patients and their significant others in Kashmir are being stigmatized, labeled and segregated as well. A woman lamented that since her husband caught coronavirus, their whole family witnessed a significant biographical shift, influencing their routine and identities as normal human beings. 'When my husband tested positive, our relatives, neighbors and friends at once abandoned us. He adopted self-isolation, and others at home also got quarantined. Anyone who went outside for medicines or groceries, faced discrimination and people were fleeing from her/him. This unjust treatment multiplied our miseries. We faced a constant social boycott as if we have committed an unpardonable crime' (P11).

Also, Mudasir recounted that people branded him with a COVID-19-inspired nickname after getting infected with it. 'Soon after testing positive with COVID-19, people started taunting me with the nickname "Muda-Covid". I have been blamed for spreading the virus among others. People associated my name with the illness I suffered, but without my will. I hardly committed any offense, but am treated like an outcast—a criminal. Why should I be banished like that? Such outrageous behavior in a Muslim community is unbelievable' (P7).

### *Post-recovery stigma*

The social stigma associated with COVID-19 patients extends much longer than the illness lasts in them which drastically affects their biographies. Coronavirus-related stigmatization is so deeply ingrained in society that the patients continue to face social exclusion, even after getting recovered. Participants shared feelings of dissatisfaction because of society's discriminatory attitude toward them, even in their post-recovery period as well. A COVID-19 survivor described how community members continue to discriminate against him and his significant others. 'After proper recovery from coronavirus, I expected a normal life again in society, but that never happened. People know that I have recovered,



but still, some of them prefer to flee from me, and my family members, as if we continue to be a threat to them. It discriminates against us, and we get traumatized. How long society will continue to devalue and alienate us, for an illness upon which we had no control? I feel humanity is dead' (P9).

The community members continue to view the COVID-19 survivors as the 'undesirable other' and not a part of the 'desirable them' which intensifies their alienation and trauma. A COVID-19 survivor described that the post-recovery stigma is more disturbing for him than had been the illness itself, as he continues to be looked upon through the prism of prejudice. 'Weeks post my recovery, I thought of meeting my friends, whom I used to miss, and called one of them, however, he refused to meet. Even today they ignore me and divert their way from seeing me. People in the vicinity too, refuse to shake hands with me, as if I am an untouchable' (P4). Another participant narrated, 'after recovery, I prepared myself to visit the parental home of my wife to have the first glimpse of our newborn daughter. However, due to stigma, my in-laws restricted me to visit their home. Such discriminatory treatment from my own people was heart-piercing. It alleviated my anxiety' (P7).

## CONCLUSION

The results of this study reveal that the economically weaker sections of rural Kashmir face grim job prospects amid lockdown, and their vulnerabilities intensify when any of their family members get infected with COVID-19. They are unaware of COVID-19 and avoid testing in the milieu of losing their jobs. They have limited access to healthcare, and due to lockdown, face extreme difficulties in transporting the sick to hospitals. Their survival gets altered, face constraints in arranging medicines, and lack basic facilities at home to isolate their infected family members, thereby experiencing their losses and struggles as biographical disruption. It can be, as such, argued that the rural poor in Kashmir are deprived of requisite facilities to adopt a healthy coping strategy, which intensifies their vulnerabilities, and are hence prone to be hit the hardest on being declared COVID-19 positive. They lie at an acute health disadvantage and, the COVID-19 crisis, further added to their marginality and socioeconomic adversity.

## IMPLICATIONS

The current study highlighted the lack of awareness about COVID-19 among people in rural areas of Kashmir, exposing them to severe health risks. Awareness regarding COVID-19, as such, should be

disseminated among villagers to encourage them to seek timely medical care. In the current COVID-19 crisis, PHC in Kashmir is overstretched, leading to improper care of patients. So, PHC needs to be equipped with adequate resources (Medina *et al.*, 2020) in Kashmir. The engagement of private hospitals with proper capping on treatment costs could also assist in meeting the increased demand for care. While advising patients for self-isolation, the hospitals must aware them regarding the effective management of COVID-19 at home and examine their health status after regular intervals of time.

Insufficient infrastructure in poor households is a disturbing finding in our study as it risks the lives of patients and their significant others. So, community isolation centers with proper facilities should be established specifically for the marginalized, to help them cope with the situation. To improve well-being during the time of crisis, mass media, NGOs and people, in general, need to extend due support and encouragement to the infected and their significant others through proper channels. They should be acknowledged as victims of the pandemic, rather than its carriers. COVID-19 will eventually end, but its socioeconomic and psychological shocks on poor communities may sustain. Understanding the nature of phenomena and crafting appropriate policy responses to mitigate these shocks should be a top priority for researchers, experts and policymakers alike.

## REFERENCES

- Akmal, A. (2021) J&K records 29 COVID deaths, lowest in 30 days. *Daily Greater Kashmir*. <https://www.greaterkashmir.com/news/front-page-2/jk-records-29-covid-deaths-lowest-in-30-days/> (last accessed 25 August 2021).
- Attanasio, O., Blundell, R., Conti, G. and Mason, G. (2020) Inequality in socio-emotional skills: a cross-cohort comparison. *Journal of Public Economics*, **191**, 104171. <https://doi.org/10.1016/j.jpubeco.2020.104171>
- Bansal, R. (2020) India has social schemes for poor in crises like COVID. But it needs a 'who to pay' database. The Print. <https://theprint.in/opinion/india-needs-a-who-to-pay-database-covid-crisis/406783/> (last accessed 22 May 2021).
- Bhattacharya, P., Banerjee, D. and Rao, T. S. (2020) The 'untold' side of COVID-19: social stigma and its consequences in India. *Indian Journal of Psychological Medicine*, **42**, 382–386.
- Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, **3**, 77–101.
- Chen, C. Y.-C., Byrne, E. and Vélez, T. (2021) Impact of the 2020 pandemic of COVID-19 on families with school-aged children in the United States: roles of income level and race. *Journal of Family Issues*, **43**, 719–740. <https://doi.org/10.1177/0192513X211994153>
- Fisher, J., Languilaire, J.-C., Lawthorn, R., Nieuwenhuis, R., Petts, R. J., Runswick-Cole, K. *et al.* (2020) Community,

- work, and family in times of COVID-19. *Community, Work & Family*, **23**, 247–252.
- House, J. S. (1981) *Work Stress and Social Support*. Addison-Wesley Publishing Co., Reading, MA, USA.
- Jafree, R. S., ul Momina, A. and Naqi, S. A. (2020) Significant other family members and their experiences of COVID-19 in Pakistan: a qualitative study with implications for social policy. *Stigma and Health*, **5**, 380–389.
- Johri, M., Agarwal, S., Khullar, A., Chandra, D., Pratap, V. S., Seth, A. and Gram Vaani Team. (2021) The first 100 days: how has COVID-19 affected poor and vulnerable groups in India? *Health Promotion International*, **36**, 1716–1726.
- Kretchy, I. A., Asiedu-Danso, M. and Kretchy, J. P. (2021) Medication management and adherence during the COVID-19 pandemic: perspectives and experiences from low-and middle-income countries. *Research in Social & Administrative Pharmacy: RSAP*, **17**, 2023–2026.
- Kumar, A., Nayar, K. R. and Koya, S. F. (2020) COVID-19: challenges and its consequences for rural health care in India. *Public Health in Practice*, **1**, 100009.
- Leavitt, J. W. (1996) *Typhoid Mary: Captive to the Public's Health*. Beacon Press, Boston.
- Lincoln, Y. S. and Guba, E. G. (1985) *Naturalistic Inquiry*. Sage, Newbury Park, CA, USA.
- Medina, M. G., Giovanella, L., Bousquat, A., Mendonça, M. H. M. D. and Aquino, R. (2020) Primary healthcare in times of COVID-19: what to do? *Cadernos de Saúde Pública*, **36**, e00149720.
- Mitra, S. (2020) The implications of COVID-19 for rural India IDR. 25 March. <https://idronline.org/the-implications-of-covid-19-for-rural-india/Google Scholar>.
- Núñez, A., Sreenganga, S. D. and Ramaprasad, A. (2021) Access to healthcare during COVID-19. *International Journal of Environmental Research and Public Health*, **18**, 2980.
- Oliveira, M., Braga, M. F., Bueno, A., de Sousa, D. P., Pigozi, P. L., Moryia, R. et al. (2021) Actions during the COVID-19 pandemic to protect the most vulnerable population: what is the potency amid chaos? *Health Promotion International*, **37**, 1–17.
- Ones, L. (2020) The COVID-19 pandemic: a family affair. *Journal of Family Nursing*, **26**, 87–89.
- Prime, H., Wade, M. and Dillon, T. (2020) Risk and resilience in family well-being during the COVID-19 pandemic. *American Psychologist*, **75**, 631–643. <https://doi.org/10.1037/amp0000660>
- Seervai, S. and Shah, A. (2021) India's failure of leadership collapses health system in COVID-19 surge. *The Commonwealth Fund*, 29 April. <https://www.commonwealthfund.org/blog/2021/indias-failure-leadership-collapses-health-system-covid-19-surge> (last accessed 16 December 2021).
- Summerton, S. A. (2020) Implications of the COVID-19 pandemic for food security and social protection in India. *Indian Journal of Human Development*, **14**, 333–339. <https://doi.org/10.1177/0973703020944585>
- The Lancet. (2020) COVID-19: remaking the social contract. *Lancet (London, England)*, **395**, 1401.
- The Lancet COVID-19 Commission. (2020) Lancet COVID-19 Commission Statement on the occasion of the 75th session of the UN General Assembly. *The Lancet*, **395**, 1102–1124. [https://doi.org/10.1016/S0140-6736\(20\)31927-9](https://doi.org/10.1016/S0140-6736(20)31927-9)
- Van Wyngaard, A. (2006) Towards a theology of HIV/AIDS. *Verbum et Ecclesia*, **27**, 265–290.
- Wani, F. (2021) J&K reports more than 72,000 COVID cases, 963 deaths in 18 days this month. *The New Indian Express*. <https://www.newindianexpress.com/nation/2021/may/20/jk-reports-more-than-72000-covid-cases-963-deaths-in-18-days-this-month-2304933.html> (last accessed 22 June 2021).
- WHO.(2020)StatementontheSecondMeetingoftheInternational Health Regulations (2005) Emergency Committee regarding the outbreak of novel coronavirus (2019-nCoV). [https://www.who.int/news/item/30-01-2020-statement-on-the-second-meeting-of-the-international-health-regulations-\(2005\)-emergency-committee-regarding-the-outbreak-of-novel-coronavirus-\(2019-ncov\)](https://www.who.int/news/item/30-01-2020-statement-on-the-second-meeting-of-the-international-health-regulations-(2005)-emergency-committee-regarding-the-outbreak-of-novel-coronavirus-(2019-ncov)) (last accessed 30 May 2021).
- WHO. (2021) Weekly operational update on COVID-19. 31 May. <https://www.who.int/publications/m/item/weekly-operational-update-on-covid-19-31-may-2021> (last accessed 01 June 2021).
- Wolka, E., Zema, Z., Worku, M., Tafesse, K., Anjulo, A. A., Takiso, K. T. et al. (2020) Awareness towards corona virus disease (COVID-19) and its prevention methods in selected sites in Wolaita Zone, Southern Ethiopia: a quick, exploratory, operational assessment. *Risk Management And Healthcare Policy*, **13**, 2301–2308. <https://doi.org/10.2147/RMHP.S266292>
- Wright, L. M. and Bell, J. M. (2009) *Beliefs and Illness: A Model for Healing*. 4th Floor Press, London, UK.
- Wright, L. M. and Leahey, M. (2013) *Nurses and Families: A Guide to Family Assessment and Intervention*. F.A. Davis Company, London, UK.