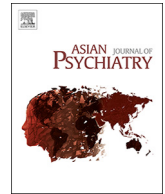




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Lived experiences of the corona survivors (patients admitted in COVID wards): A narrative real-life documented summaries of internalized guilt, shame, stigma, anger



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ABSTRACT

COVID-19 pandemic has emerged as a disaster for the human beings. All the Governments across the globe have been preparing to deal with this medical emergency, which is known to be associated with mortality in about 5% of the sufferers. Gradually, it is seen that, many patients with COVID-19 infection have mild symptoms or are asymptomatic. Due to the risk of infecting others, persons with COVID-19 infection are kept in isolation wards. Because of the isolation, the fear of death, and associated stigma, many patients with COVID-19 infection go through mental distress. In this report, we discuss the experience of 3 persons diagnosed with COVID-19 infection and admitted to the COVID ward.

1. Introduction

The COVID-19 pandemic has taught the entire human fraternity a big lesson. It is a severe blow to the healthcare system of the entire world and had affected millions of people across the world. COVID-19 is associated with a very high rate of infectivity, which has led to a high level of fear and anxiety of getting infected. Resultantly, the pandemic has led to severe restrictions on the free movements of human beings, and the lockdown of almost all countries across the World, etc. The literature on laboratory testing, preventive measures, and management protocols to tackle the highly infective virus are ever-expanding. Even the data related to the mental health issues in the front line warriors/health care workers is well-documented.

However, the real-life experiences of the patients admitted in the COVID wards and their well-being in the COVID-19 era is largely neglected. There are few blogs/youtube videos of the recovered patients/Corona survivors about their experience (about how they had fought with the infection, how much they felt lonely during the admission etc.) during their hospital stay, yet no descriptive data is available (Busby, 2020; Collinson, 2020; KWCH, 2020; What Does COVID-19 Feel Like? One Patient Shares His Experience [WWW Document], 2020). In this report, we discuss the psychological issues and the lived experiences of 3 persons who were admitted with the COVID-19 infection during their

hospital.

1.1. Covid-19 setting

The COVID-19 designated center is being managed by a core COVID-19 team consisting of doctors from Internal Medicine, Anesthesia, Pulmonary Medicine, and Hospital administration. During the initial few days, it was seen that most patients admitted with the infection had some or other mental health issues such as anxiety, excessive worries, irritability, low mood, frustration, distress, feeling isolated/loneliness, etc. This led to the involvement of mental health professionals to provide mental health support through video-conferencing/telephonically. The 3 summaries discussed in this report are the mental health issues and other experiences shared by 2 persons and a family admitted in the COVID center.

2. Lived Experience: “Dilemma of being a leader- why did I infect others, how will I face my colleagues?”

49 years old male, a village leader, was admitted after he was found to be COVID-19 positive. As reported by him, as far he recollects, he possibly got infected during the visit to the hospital. He did not have any severe respiratory distress during the hospital stay and after 3–4

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days of flu-like symptoms and fever, he became stable. During the initial few days of hospital stay, he would rarely talk with his family members over the phone. After he became medically stable, he came to know that 9 of his family members have also been infected and are admitted to a different hospital. He started remaining worried about their well-being. He would have frequent night time awakenings, which were associated with palpitations, sweating, and feel restless. He would have racing thoughts about the well-being of his children (9 and 15 years) and his wife. He would doubt the treating team, and as to whether they are telling him the truth about the well-being of his other family members. Within a day or two, while telephonically interacting with his friends, he came to know that 38 persons from his village have been infected and all have been traced to him as he had attended a meeting where more than 50 villagers had come. This further increased his distress and anxiety. This information led to significant guilt, and he started blaming himself for the fate of others. He started calling fellow villagers to enquire about the health and well-being of villagers and after knowing that all are doing well, would temporarily feel relieved. He started blaming himself for his carelessness, would feel shameful, and guilty of his act. He would remain preoccupied with thoughts as to what villagers would be thinking about him, will they ever forgive him, will they maintain a good relationship with him in future, whether his family members will recover or not. Such thoughts would persist for most of the day. He would also remain preoccupied with thoughts such as 'how would he face his friends, neighbours, and fellow villagers'. He would often worry that in future himself and his family members will be outcasted, and he losing his political career. He did not have any history of mental illness or any history of substance use. A diagnosis of Acute Stress Reaction was considered. Supportive sessions were taken by the psychiatrist by teleconferencing. All his concerns were heard and his anxiety related to his worries was allayed. During the sessions, he came up with his worries, expressed his inability to help his family members, about his future, and the anticipated stigma. With the supportive sessions, he started feeling better and relaxed. Besides supportive sessions with the patient, one of his cousin (uninfected) with whom the patient was in constant touch was involved in the treatment, who was asked to motivate the patient to stay active and remain busy watching videos/movies on YouTube channels, read things of his likings on the internet and pray to God. He was discharged after his repeat tests came out to be negative. He is being followed up telephonically, supportive sessions are being continued to avoid any other negative psychological consequences.

3. Lived Experience: "the troubled family - A Couple with their 10-month-old baby"

A family comprising of the couple, who had recently traveled to India, and their 10-month-old child were admitted to the COVID ward, after being found positive for the infection. The husband was 35 years old and the wife was 32 years old. Both, the husband and the wife had minimal physical symptoms during the initial 2-3 days. However, psychologically, both of them felt angry about themselves, especially about their decision to come to India to visit their family, cursed their fate, and would remain apprehensive about the outcome of their baby. The mother would frequently check the baby for any rise in body temperature and would get very anxious if the baby would cry. The couple was also very much distressed because of the non-availability of air-conditioning, which was maintained with less venting to prevent air circulation and aerosol generation. On the 3rd day of their admission, their 8 years old daughter and the mothers of both the partners (59 years and 57 years old) tested positive. The mother of the male partner was admitted at our center, went on to develop respiratory distress, and had to be shifted to the COVID intensive care unit (ICU). This triggered a deep sense of 'guilt' in the male partner and he started having thoughts that '*I infected my mother and my daughter*', '*Will my mother be able to survive*', and '*Will I be able to see her again*', etc. He started

following the updates about COVID-19 infection in India and the world more closely, started to remain worried and tensed when he would see the mortality rates/figures of India and of the World in which the elderly are at extreme risk. His partner would be also going through similar mental issues. The couple would discuss their worries with each other, would try to reassure each other. But they would get more worried when they would stay away from each other (as they were isolated i.e. had to stay in different rooms – a mother with the baby and father alone). The couple would keep on calling the relatives to know about the progress of other relatives and check with the hospital staff about the progress in the health of their mothers/ mother-in-laws. Over the next 1-2 days, the psychological symptoms worsened and the female partner started remaining irritable and distressed, would repeatedly ask about her discharge date. When she was explained that she would be discharged after a particular time frame, the female partner started arguing with the health care professionals on duty. Gradually the tussles increased significantly and led to the intervention by the psychiatrist. The female was assessed by teleconferencing and all her worries were heard. A diagnosis of Acute Stress Reaction was considered and supportive psychotherapy was started. Initially the patient was allowed to ventilate her worries and concerns. This led to a reduction in her distress and anxiety. Steps were taken to look after the welfare of the couple, i.e. allowing them to meet 2-3 times a day with precautions of hand hygiene and social distancing. After 2-3 days, things started to settle, the mother of the male partner admitted to ICU became stable and was shifted to the ward. This led to a further reduction in worries and distress. After 14 days when the couple was tested to check for their COVID-19 status, the husband and wife were found to be negative but to their 10-month-old child was still found to be positive. This led to further frustration and distress in the female partner. She would remain irritable, get angry at the staff, and would argue about the credibility of the tests being done, etc. These issues were again addressed in the ongoing supportive sessions, in which she was allowed to vent out her anger and was explained about the testing protocol, sensitivity, and specificity of the test and the implications of discharging people if they are still positive for COVID-19. This led to a reduction in her distress. After mutual agreement, it was decided to discharge the male partner and the female partner, who stayed in the hospital, along with the infant, till the child became negative for COVID-19 infection. Both the partners are continued on the supportive sessions.

4. Lived experience: "the computer savy boy and his agony"

A 23 years old man was admitted after being tested positive for COVID-19, who had contracted the infection after meeting a friend who returned from abroad. He described his experience of initial few days of being angry on his friend, would call his friend (who was admitted in another hospital- medically stable), would abuse him for infecting him and would ask him never to show his face again to him. He would be worried about his parents, who had multiple physical co-morbidities and would be pre-occupied with their COVID-19 status. His parents and other family members were tested and none of them were found to be positive. He did not have any severe respiratory difficulty and was medically stable throughout his stay. By the second week of his stay in the COVID-19 ward, he started to report that he is feeling bored, he would not find surfing the Internet to be enjoyable anymore, would keep on moving inside his room and look outside through the windows of his room. While on routine screening by the mental health professional telephonically, he expressed difficulty in passing his time. He expressed that he missed his computer/laptop, want to play video games, and would demand the same. Gradually his distress started increasing. Supportive sessions were taken and the activity schedule was planned for him. He was asked to make an activity schedule for himself and watch music videos of his choice. On exploring his hobbies it became apparent that besides, playing video games, he also pursued

photography as an alternate hobby. He was given daily tasks by the text messages, as to see photography from specific sites of his choice and send it to the psychiatrist by using the Whatsapp. He was asked to look for any online photography training and to remain busy in gaining more knowledge of photography. After 3rd day of starting the intervention, he reported that he was able to spend his time in interesting things, which he always wanted to pursue. He reported, *"Sometimes I feel like I am in jail but then when I remember it is a temporary phase, I can control my emotions, I never tried to show my agony and pain to my parents and I feel cheered up when I get your (psychiatrist's) message or call"*. He was tested negative after 16 days and was congratulated for his recovery at discharge. He is being followed up and the supportive therapy is being continued.

5. Discussion

The above-mentioned narrative lived experiences of the COVID-19 survivors or patients admitted to the COVID ward are beyond one's imagination. The stress, mental agony, internalized stigma, feelings of guilt of infecting near and dear ones, the shame of infecting others, anger directed towards self, cursing one's fate, thinking "why God has punished me and my family" adds on to the pain of remaining socially isolated from the family in a 'locked up' state is highly distressing. All these issues suggest that mental health is taking a big toll on the people diagnosed with COVID-19 infection and admitted to the COVID wards. The systems are preparing themselves to deal with more severe cases, i.e., those who are going to require ICU and ventilator support, but the mental health of a major proportion of people, who are going to develop mild to moderate symptoms of COVID-19 infection is not being discussed. These lived experiences of the people bring to the forefront the issue of "No health, without Mental Health". As is evident from these cases, the mental health issues would not have come to the forefront, if the mental health professionals were not involved in the management of these cases. This could have led to severe untoward consequences, such as relationship issues between the patient and the treating team and the patients progressing to severe depression. In these above mentioned narrative experiences, timely psychological evaluation, and brief supportive sessions carried out telephonically or by video conferencing helped the people going through the infection. Mental Health professionals need to recognize that besides anxiety, depression, and insomnia, guilt, anger, frustration and internalized stigma are also going to be the major issues of these patients and they need to address the same.

These case descriptions suggest that apart from the psychological issues of the health care workers, there is an urgent need to handle and understand the mental health issues of the patients suffering from COVID-19 during admission/ward stay and during quarantine (Banerjee, 2020). The uncertainty of having a dreadful illness, limited family support, fear of death of self, and near ones imposes a severe stressful mental state, and therefore mental health evaluation and mental health support to the patients' needs to be routinely done.

World Health Organisation mentions that psychological issues need to be taken into considerations during the COVID-19 pandemic for the general public (World Health Organization, 2020). Many authors have also stressed the psychological first aid to be provided to the patients admitted in the COVID wards (Li et al., 2020; Xiang et al., 2020).

Based on our experience we suggest that all the COVID-19 wards and services should be planned keeping the mental health of the people at large. All COVID wards and other services should have mental health professionals, who should be involved right from the time of screening the persons for COVID-19 (Grover et al., 2020). The mental health professionals involved with the COVID-19 wards should screen all the patients daily and address their issues and the interpersonal issues arising as a result of isolation and other ensuing issues. As many patients would be asymptomatic or would gradually become asymptomatic and stable after the initial few days, the stress and isolation would come to the forefront and will become an issue rather than any other medical/clinical issue. Routine evaluation by mental health professionals should be a part of the treatment protocol which is at present not mentioned/documented for holistic management of stigmatized, aggrieved corona fighters, and survivors. Further, psychiatrists and mental health professionals should be prepared to tackle with post-COVID era mental health consequences too (Das, 2020).

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Declaration of Competing Interest

None.

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