Self-reported perspectives, Lived experiences and Assessment of COVID-19 survivors in India from media and social media during Nationwide lockdown: A Preliminary study

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Abstract

Background: Coronavirus disease 2019 (COVID-19) pandemic poses a tremendous threat as a rapidly spreading disease, and has significant consequences on the global public health in particular to the psychological aspect of the survivors. The lived experiences require urgent documentation to tailor-make psychiatric assessments and long-term follow-ups. Aim: To explore adolescents’ self-reported perspectives and lived experiences during their COVID-19 illness which was voluntarily shared through media and social media platforms during the nationwide lockdown in India. Methods: Being a preliminary study, the sample size was calculated as 20 based on similar studies in the literature. Voluntarily shared data of COVID-19 survivors were extracted from media and social media. Based on the data, an assessment sheet was prepared, pre-tested and shared with three observers via convenient sampling. Results: Male predominance was noted. The mean age was found to be 39.5 years. English was the most commonly uploaded language to communicate suffering. Instagram and YouTube were the most prevalent social media sites for self-reported experiences. The most prevalent physical symptom was fever and cough. Stress, anxiety and stigmatization were more commonly reported. Statistical significance was obtained between fear and end of life, depression and suicide, pain and isolation and worried with insomnia. Conclusion: COVID-19 not only affects physical health but also takes a toll on the mental health of the patients. There is a high prevalence rate of psychological distress among COVID-19 survivors, and we recommend a formal psychiatric assessment and long-term follow-up to understand the unique challenges faced by the COVID-19 survivors, with effective communication and empathy towards them.

Keywords: COVID-19, COVID-19 perspective, COVID survivors’ emotional experiences, pandemic, psychological impact of COVID-19

Introduction

Infectious diseases are the biggest threat to humans causing significant death and morbidity.\cite{1-4} Coronavirus disease 2019 (COVID-19) is caused by severe acute respiratory syndrome-2 (SARS-CoV-2), also known as Novel coronavirus (2019-nCoV), which was first isolated in Hubei, China in December 2019. On 11 March 2020, World Health Organization declared the COVID-19 caused by 2019-nCoV as a global pandemic.\cite{5,6} The COVID-19 pandemic poses a tremendous threat as a rapidly spreading disease, and has significant consequences on the global public health in particular to the psychological aspect of the survivors.

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Post-pandemic, a nationwide lockdown was implemented to contain the spread along with infection control protocols. Following this, social media was flooded with pandemic jargons and survivors started to open up in media and social media to share their personal experiences as being an unprepared pandemic patient.\textsuperscript{[6-8]} Due to physical constraints of lockdown, it is difficult to connect with the survivors face-to-face nor collect details from health sectors regarding the contact details of the survivors. Most of the literature data focus on the psychological impact of healthcare workers and not the sufferers. Hence, to fill this gap in the literature, this unique and unexplored study focused on the psychological impact of the sufferers to urgently synthesize the documentation. In this context, this study is an important addition to the existing literature.

**Aim**

To explore adolescents’ self-reported perspectives and experiences during their COVID-19 illness which was voluntarily shared through media and social media platforms during the nationwide lockdown in India.

**Objectives**

**Primary objectives**
- To assess the physical, psycho-social and emotional experiences among COVID-19 survivors.

**Secondary objectives**
- To estimate the prevalence of physical, psycho-social and emotional health problems experienced by the COVID-19 survivors.

**Methodology**

**Study design**

This pan India, retrospective, preliminary, cross-sectional study was designed by the principal investigator of the study during the COVID-19 pandemic nationwide lockdown. This study was approved by the Institutional Ethical and Scientific Committee Board (IRB number-165/IRB-IBSEC/SIST).

**Study sample**

During the framework of this research, not much related studies were available in the literature. Hence, being a preliminary attempt, the sample size was derived at 20 as per the formula shown in Figure 1 based on a literature search. COVID-19 survivors who had voluntarily shared their experiences in media and social media constituted the study sample.

**Search strategy and data collection**

Using multiple keywords which include ‘Covid-19 experiences from survivors’, ‘Covid-19 impact on survivors’ and ‘Pandemic survivors’ to name a few, data from various social media forum databases (like Facebook, YouTube, Twitter, Instagram, clubhouse etc) and media including from various webpages of national and international health organizations (online interview reports in magazines and newspapers, testimonials etc.) were extracted, where COVID-19 survivors had voluntarily posted/opened up to share their COVID-19 perspective/emotional experiences through selfie videos and as testimonials. The data collection period was for 10 months from March 2020 to December 2020.

**Informed consent**

Only those data where the COVID-19 survivors have voluntarily opened up to the media and social media under their own consent for creating publicity or awareness were chosen for the study, and also all the data used are still available in their respective sources for future research purposes.

**Inclusion criteria**

- Videos or testimonials of COVID-19 survivors only from India,
- Freely available, voluntarily uploaded, selfie videos and testimonials in social media and media forums,
- Data in Tamil, Malayalam, Hindi and English languages,
- Data irrespective of gender.

**Exclusion criteria**

- Known COVID-19 survivors who have not voluntarily uploaded/shared their experiences in any of the media/social media forums,
- Videos or testimonials of international COVID-19 survivors regarding their illness,
- If the video content had blamed political parties or health sector along with sharing their experiences,
- Paediatric/patient videos below 18 years,
- Videos shot by another person/caregivers,
- Paid sources since the study is self-funded.

**Assessment strategy**

Based on the media and social media hunt, self-reported COVID-19 survivor’s experiences (physical, psychological, social and emotional) were documented to assess via an assessment sheet containing 25 closed-ended questions without pandemic jargons, as shown in Table 1. The assessment sheet is to examine the impact (physical, psychological, social and emotional) of...
the viral pandemic on the survivors. Personal details of the study subjects were not recorded, which included their names and permanent residence address. However, state of residence, gender and age were noted as part of the data for descriptive statistics. None of the videos was downloaded from the sites to ensure cyber safety. The assessment sheet was pre-tested with a virtual interview with known pandemic survivors from the study institution who were willing to share their experiences under consent. The assessment sheet was prepared by the study investigator based on the available sample data to assess and interpret each video/testimonial based on the objective of the study. On viewing each video/testimonial, the sheet was filled by three randomly selected observers from the study institution and selected by the principal investigator through convenient sampling. Physical symptoms were also documented to study the prevalence and were reviewed by the observers along with additional data which were also shared. All three observers were blinded to the study’s purpose and outcome. Additionally, language translators were used whenever needed for the observers. Two and more than two same responses from the observers were taken as final data for statistical analysis. All the observers were given adequate privacy to fill out the assessment sheet to avoid distractions from a third party.

Table 1: Assessment sheet comprising 20 closed-ended questions without pandemic jargons

| Age/sex | Aspect                                      | Answer        |
|---------|---------------------------------------------|---------------|
| /M/F    | Was the word Stress used?                   | Yes/No/Not sure |
| /M/F    | Was the word ‘Anxiety’ used?              | Yes/No/Not sure |
| /M/F    | Was the word ‘Depression’ used?             | Yes/No/Not sure |
| /M/F    | Was the word ‘Feeling of left alone’ used? | Yes/No/Not sure |
| /M/F    | Was the word ‘Worried’ used?               | Yes/No/Not sure |
| /M/F    | Was the word ‘Waiting to see family’ used? | Yes/No/Not sure |
| /M/F    | Was the word ‘Feeling of rejection’ used?  | Yes/No/Not sure |
| /M/F    | Was the word ‘Suicide’ used?               | Yes/No/Not sure |
| /M/F    | Was the word ‘Dying/Death’ used?           | Yes/No/Not sure |
| /M/F    | Was the word ‘Stigmatizing’ used?          | Yes/No/Not sure |
| /M/F    | Was the word ‘Tired’ used?                 | Yes/No/Not sure |
| /M/F    | Was the word ‘Guilt’ used?                 | Yes/No/Not sure |
| /M/F    | Was the word ‘Financial constraint’ used?  | Yes/No/Not sure |
| /M/F    | Was the word ‘Debt’ used?                  | Yes/No/Not sure |
| /M/F    | Was the word ‘Scared’ used?                | Yes/No/Not sure |
| /M/F    | Was the word ‘Expensive’ used?             | Yes/No/Not sure |
| /M/F    | Was the word ‘Panic’ used?                 | Yes/No/Not sure |
| /M/F    | Was the word ‘Fatigue’ used?               | Yes/No/Not sure |
| /M/F    | Was the word ‘Insomnia’ used?              | Yes/No/Not sure |
| /M/F    | Was the word ‘Family’ used?                | Yes/No/Not sure |
| /M/F    | Was the word ‘God’ used?                   | Yes/No/Not sure |
| /M/F    | Was the word ‘Why me’ used?                | Yes/No/Not sure |
| /M/F    | Was the word ‘Anger’ used?                 | Yes/No/Not sure |
| /M/F    | Was the word ‘Positive hope’?              | Yes/No/Not sure |
| /M/F    | Was the word ‘End of life’ used?           | Yes/No/Not sure |

Assessment of physical experiences of COVID-19 survivors

During COVID-19 illness 85% of our subjects had one or more physical symptoms and 3% were asymptomatic; 25% had body pain, 80% had fever as a major symptom and 70% had issues of insomnia due to fear and anxiety. Of our subjects, 80% opened up that they had disturbances in taste, and among them, 55% had complete loss of taste; 65% of our subjects had altered smell and 35% among

Statistical analysis

The statistical software IBM SPSS statistics 20.0 (IBM Corporation, Armonk, NY, USA) was used for the analyses of the data. Descriptive and inferential statistical analyses were carried out in the present study. The level of significance was fixed at $P < 0.05$ and any value $\leq 0.05$ was considered to be statistically significant. The Chi-square test, which is a statistical test for categorical data, was performed to assess the associations.

Results

Our study covered data from 20 subjects who were the survivors of the COVID-19 pandemic in India. Male predominance was observed in our study as shown in Figure 2. The age of the subjects ranged from 27 to 52 years, and the mean age being 39.5 years. The percentage prevalence of the most commonly reported language in our sample is shown in Figure 3. The source distribution of the samples is illustrated in Figure 4. Most of the study sample uploaded videos not from their state of nativity due to issues of travel restrictions, lockdown and work from home. Hence, the videos were uploaded from different states across India as a mixed bag, making the reports for the most prevalent state of survivor experience questionable. Table 2 refers to the frequency distribution. The most prevalent physical symptom was fever, cough and tiredness, followed by gastrointestinal symptoms, taste disturbance and joint pain. The most commonly reported psycho-social issues were found to be stress, anxiety, loneliness and stigmatization, followed by financial problems and mental agony.

Figure 2: Distribution of gender

Male: 60%, Female: 40%
them had complete loss of smell; 85% had respiratory symptoms of cough and cold. Other physical symptoms included 75, 65, 85 and 10% of headache issues, joint pain and gastrointestinal tract (GIT) disturbances and breathing difficulties, respectively.

**Assessment of psycho-social, spiritual and emotional experiences of COVID-19 survivors**

All our subjects reported that their COVID time was stressful and they had anxiety issues with self-panicking and also were worried about stigmatization by neighbours or office colleagues. Of our subjects, 35% had depression feeling initially and slowly they were able to regain positivity, but they also at times felt that it is their end of life; 65% reported mental agony; 80% felt social isolation and felt that the treatments were expensive; 100% of the study subjects reported that financially they were worried when they heard that they tested positive for COVID-19; and 55% among them were scared since they were not prepared with Covid insurance and might end up in debt. Of our subjects, 90% had the feeling of social rejection; 10% had trust breach on God, felt anger on society and also expressed that they felt like dying. Around 7% of survivors faced emotional weakness, but 85% had a positive hope that they will be able to recover.

**Assessment of additional data from COVID-19 survivors**

Q1–Q5 was the additional information collected which was also studied. Of our subjects, 50% had known another COVID positive person who was either quarantined/hospitalized or expired due to COVID, and 100% of our subjects were worried about their close contact family members at home. Only 10% of our subjects were able to track their contact history and 35% of our subjects were hospitalized when they were actively infected with COVID-19.

**Associations**

Chi-square test showed statistical significance as shown in Table 3, between fear and end of life, depression and suicide, pain and isolation and worried with insomnia, with P value <0.05. No statistical difference was found between gender and fear, stress, anxiety and depression, gender and stress, stigma and rejection, anxiety with a feeling of rejection, gender with stress and gender with financial constraint.

| Parameter                                                                 | n (Yes) | % | n (No) | % |
|---------------------------------------------------------------------------|---------|---|--------|---|
| Symptoms                                                                  | 17      | 85 | 3      | 15|
| Stress and anxiety                                                        | 20      | 100|-       | - |
| Fever                                                                     | 16      | 80 | 4      | 20|
| Depression                                                                | 7       | 35 | 13     | 65|
| Panic for self                                                            | 20      | 100|-       | - |
| Worried and waiting to see family mingle                                   | 20      | 100|-       | - |
| Loneliness/feeling of isolation                                           | 16      | 80 | 4      | 20|
| Rejection                                                                 | 18      | 90 | 2      | 10|
| Suicide                                                                   | -       | -  | 20     | 100|
| Dying                                                                     | 2       | 10 | 18     | 90|
| Stigmatising                                                              | 20      | 100|-       | - |
| Tired                                                                     | 20      | 100|-       | - |
| Body pain                                                                 | 5       | 25 | 15     | 75|
| Financial                                                                 | 20      | 100|-       | - |
| Debt                                                                      | 9       | 45 | 11     | 55|
| Scared                                                                    | 11      | 55 | 9      | 45|
| Expensive                                                                 | 16      | 80 | 4      | 20|
| Mental agony                                                              | 13      | 65 | 7      | 35|
| Insomnia                                                                  | 14      | 70 | 6      | 30|
| End of life                                                               | 7       | 35 | 13     | 65|
| Cough and cold                                                            | 17      | 85 | 3      | 15|
| Breathing difficulties                                                    | 2       | 10 | 18     | 90|
| Taste disturbances                                                        | 16      | 80 | 4      | 20|
| Altered taste                                                             | 16      | 80 | 4      | 20|
| Complete loss of taste                                                    | 11      | 55 | 9      | 45|
| Smell disturbances                                                        | 13      | 65 | 7      | 35|
| Altered smell                                                             | 13      | 65 | 7      | 35|
| Complete loss of smell                                                    | 7       | 35 | 13     | 65|
| Headache                                                                  | 15      | 75 | 5      | 25|
| Joint pain                                                                | 13      | 65 | 7      | 35|
| GIT disturbances                                                          | 17      | 85 | 3      | 15|
| Feeling of emotionally weak                                               | 7       | 35 | 13     | 65|
| Why God this to me, I never thought off                                   | 2       | 10 | 18     | 90|
| Anger on society                                                          | 2       | 10 | 18     | 90|
| Having a positive hope to recover                                         | 17      | 85 | 3      | 15|
| Q1: Known a person who expired due to COVID-19                             | 10      | 50 | 10     | 50|
| Q2: Known a person quarantined due to COVID-19                             | 10      | 50 | 10     | 50|
| Q3: Both Q1 and Q2                                                        | 9       | 45 | 11     | 55|
| Q4: Panic and worried for others in family/at home                        | 20      | 100|-       | - |
| Q5: Contact history                                                       | 2       | 10 | 18     | 90|

**Figure 3:** Distribution of language

**Figure 4:** Distribution of media and social media forums
Prolonged hospitalization or stigma during the COVID treatment might have disturbed patients' inner feelings subconsciously which might be a reason for their openness in sharing their experiences on social media for social connectedness, autonomy acquisition and identity development, thus forcing adolescents to re-organize their personal resources. Socializing through social media is also spoken well to manage burn out in health care professionals. Maybe if an online forum is not available, survivors could have had relationship issues between their family and health care team, and might progress to severe depression without being able to combat their perspectives or sharing their experiences with someone.

Antoinette M. Lee conducted research on stress and psychological distress among SARS survivors 1 year after the outbreak and found that SARS survivors still had elevated stress levels and they worried about their levels of psychological distress. The study also concluded that the long-term psychological implications of infectious diseases should not be ignored and mental health services could play an important role in rehabilitation.[16] Adel F. Almutairi et al. conducted research to explore the experiences of health care providers who survived MERS-Cov in Saudi Arabia and found out that the survivors suffered traumatic experiences and negativism influencing their performances.[15] Chi-square test showed statistical significance between fear and end of life, depression and suicide, pain and isolation and worried with insomnia, with P-value <0.05. Grover evaluated the psychological impact of lockdown due to the COVID-19 pandemic on the general public in India by an online survey and reported that more than two-fifths of the people are experiencing common mental disorders, due to lockdown and the prevailing COVID-19 pandemic.[14]

Routine evaluation by mental health professionals should be a part of the treatment protocol which is at present not mentioned/documentated for holistic management of stigmatized, aggrieved corona fighters, and survivors.[17,18]

**Discussion**

Owing to isolation, fear of death and associated stigma, many patients with COVID-19 infection go through mental distress. Male predominance was observed in our study which is in accordance with the previous data reported in a Philippines population by Abad et al.[9] The mean age in our study was found to be 39.5 years, which is not in accordance with the previous study by Fioretti C in an Italian population with a higher sample size.[10] Instagram and YouTube had the highest number of shared COVID-19 experiences which cannot be compared with any other previous studies since ours is the first study to bring data from media and social media. Fever, cough, headache, tiredness, GIT disturbances and joint pain were the most commonly reported symptoms by our subjects, which is in accordance with the previous reports by Huang et al. and Wang et al.[11,12]

The most commonly reported psycho-social and emotional issues were found to be stress, anxiety, loneliness and stigmatization, followed by financial problems and mental agony, which is in accordance with a similar study reported by Jalloh to study the impact of Ebola experiences in Sierra Leone.[13] Most of our study subjects had reported symptoms of anxiety, depression, insomnia, anger, frustration and internalized stigma which is in accordance with the report by Sahoo et al.,[14] who had narrated the lived experiences of COVID-19 survivors from Chandigarh hospital, India.

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 and thinking ‘why God has punished me and my family’ add on to the pain of remaining socially isolated from the family in a ‘locked up’ state, which 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. These lived experiences of the people bring to the forefront the issue of ‘Nil health, without Mental Health’.

**Table 3:** Associations by Chi square test

| Associations by Chi square test | No  | (%) | Yes   | (%) | P    |
|--------------------------------|-----|-----|-------|-----|------|
| Fear and End of life           | 9 (100) | 0 | 4 (36.4) | 7 (63.6) | 0.004* |
| Depression and Suicide         | 13 (100) | 0 | 3 (42.9) | 4 (57.1) | 0.007* |
| Panic and isolation           | 4 (57.1) | 3 (42.9) | 0 | 13 (100) | 0.007* |
| Worried and Insomnia           | 6 (60) | 4 (40) | 0 | 10 (100) | 0.005* |
| Gender and Fear               | 5 (62.5) | 3 (37.5) | 4 (33.3) | 8 (66.7) | 0.21 |

*P < 0.05 and any value less than or equal to 0.05 was considered to be statistically significant.

**Limitations**

In this study, we struggled to beat the required miniature, workable sample size, due to the sensitivity of the topic and very limited reports on Indian patients. The possibility of making inaccurate predictions or assumptions on the basis of pilot data is higher and a detailed psychological assessment scale was not used, however, the responses were assessed via a pre-tested sheet and reviewed by three observers to minimize the bias. Second, the majority of our subjects had only mild COVID-19 infections and they did not reveal any of their co-morbid conditions, hence holistic documentation was not possible in terms of addressing total pain. We could not collect the true incidence of pre-existing mental illness. Third, confounding factors were not addressed as it was not mentioned by the survivors. The study was limited to those, who had access to a smartphone device which can facilitate ease to all social media platforms. Finally, an online assessment has its own limitations. Although this study explored the...
experiences of only a limited number of survivors, it produced trustworthy insights. Possibly, a higher sample size with a better study design could definitely minimize the data contamination from COVID-19 survivors to maximize the reliability of the study results. However, considering the situation, this was the possible best methodology to understand the psychological impact of the sufferers. These limitations suggest that the findings may not be generalizable to every stratum of society.

**Conclusion**

COVID-19 not only affects physical health but also takes a toll on the mental health of the patients, as documented by our study. There is a high prevalence rate of psychological distress among COVID19 survivors, and we recommend a formal psychiatric assessment and long-term follow-up to understand the unique challenges faced by the COVID-19 survivors, with effective communication and empathy towards them.[9] Also, enormous data are available on the media and social media, which can be utilized for future projects. We believe our findings will provide specific insights into making an open platform for further research and preparedness for the public and health care workers in this very special scenario of a disaster. A lot is spoken about communication and compassionate caring for cancer patients, and it is time to bring the same empathy and awareness to COVID-19 survivors.[8] This study is a pioneering attempt at the grassroots level. Further longitudinal studies are recommended to investigate the development of COVID-19 survivors’ resilience over time for timely mitigation to improve their overall quality of life.

**Author's contribution**
The authors have contributed to the entire preparation of the manuscript.

**Ethical approval**
Taken.

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**Conflicts of interest**
There are no conflicts of interest.

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