Psychosocial Impact of Pandemic and State Imposed Lockdown on Caregivers of Patients Presenting with Respiratory Complaints Mimicking COVID-19: A Short-term Follow-up Study

Public Health Section

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# ABSTRACT

**Introduction:** Pandemics and subsequent lockdowns affect mental health of different subgroups of populations. In Coronavirus Disease-2019 (COVID-19), caregivers of those patients who have respiratory complaints is one such subgroup which is more vulnerable to disturbances in mental health, because of the fear that their patient's respiratory symptoms could be because of COVID-19.

**Aim:** To assess the psychosocial impact of COVID-19 and subsequent state imposed lockdown on the caregivers of patients presenting with respiratory complaints and also to evaluate the effect of relaxation of lockdown after following-up them over a period of time.

**Materials and Methods:** This prospective observational study was conducted in the Department of Pulmonary Medicine, Government Medical College, Patiala, Punjab, India (tertiary care institute), from April 2020 to June 2020. Baseline assessment was done using socio-demographic proforma, lockdown related questionnaire {3 domains, summed as total score (lockdown)}, COVID-19 related questionnaire {total score (COVID-19)} and General Health Questionnaire-12-Hindi version (GHQ-12). Reassessment was done twice i.e., at 11-15 days and 41-45 days after relaxation of lockdown. Quality Of Life (QOL) at first and second follow-up versus prelockdown times (score A and C) and first follow-up versus unlockdown (score B) was also noted.

Analysis was conducted using Statistical Package for Social Sciences (IBM, SPSS)version 22.0.

Results: Total 65 caregivers were enrolled in the study. Mean age of the participants was 40.2±11.812 years with maximum caregivers 25 (41.7%) aged between 31-40 years. Majority (83.3%) were men. Psychological distress was experienced in 50% of caregivers at baseline and 23.7% caregivers at first follow-up (p-value=0.001). Worry for COVID-19 (p-value=0.035), Domain 1 scores (p-value <0.001), Domain 2 scores (p-value=0.003), Domain 3 scores (p-value=0.001), and Total score lockdown (p-value <0.001) decreased significantly at first follow-up. Mean C score was significantly better than mean A score (p-value <0.001). Baseline psychological distress was significantly more in those with worry for COVID-19 (p-value=0.018), poorer scores of domains 1 (p-value=0.005), domains 2 (p-value <0.001), domains 3 (p-value <0.001), total score (lockdown) (p-value <0.001) and total score (COVID-19) (p-value=0.010). Follow-up psychological distress was more in those with "worry for COVID-19" (p-value <0.001), negative thoughts (p-value=0.001), poorer follow-up scores of three domains, total score (lockdown), mean A, B and C scores (p-value < 0.001).

**Conclusion:** Caregivers experienced extreme levels of psychological distress, which decreased, but persisted even after relaxation in lockdown.

# Keywords: Coronavirus disease-2019, Mental health, Psychological distress

# INTRODUCTION

Coronavirus Disease-2019 (COVID-19) pandemic shook the world unexpectedly and brought life to a standstill [1]. Various countries underwent strict lockdowns as a social distancing measure to prevent the spread of infection to the masses. In the state of Punjab, complete lockdown was announced on 22<sup>nd</sup> March, 2020, during which only essential services were allowed [2]. Subsequently, 21 days strict nationwide lockdown was announced in India on 24<sup>th</sup> March 2020 [3]. The lockdown was extended in phases one after the another. In Punjab, it was eased for a few hours since its first imposition on 30<sup>th</sup> April, 2020 [4].

The COVID-19 and lockdown measures caused disturbances in mental well being. Various advisories were issued by World Health Organisation (WHO) and Ministry of Health and Family Welfare (MOHFW), Government of India for the protection of mental health [5-10]. However, the recommendations were by and large ignored. Enough evidence has generated that the unprecedented strict

lockdown measures are a threat to mental health and overall well being, as we juggle through different waves of the pandemic [11-19]. However, studies remain focused on specified subgroups of vulnerable populations like healthcare professionals, children, elderly, patients suffering from chronic ailments [11-19].

It is known that different groups of people as per their age, sociodemographic profile, type of personality and mental makeup may respond differently to a given situation. The responses also differ markedly with innumerable confounders like underlying disease, comorbidities, suffering in a family member and so on [20]. Caregivers is one such distinct group which needs attention. Mental well being of caregivers of patients with chronic illnesses has been studied in the past in non pandemic situations [21,22].

The existing COVID-19 literature has investigated the mental health of caregivers of some special subgroups like caregivers of cancer patients, health professionals as caregivers of COVID-19 patients, caregivers of children and adolescents with psychological

disturbances, caregivers of people with dementia [23-27]. However, caregivers of patients with respiratory complaints have not been studied in this pandemic.

The state of Punjab and the nation had witnessed steep rise in case numbers and had battled through the devastating second wave of the pandemic [28,29]. The fear of COVID-19 for their patients, because of the similarity in clinical presentation, is expected to have a distressing effect on the metal well being of the caregivers. Infectiousness of the disease, resultant isolation, stigma and lockdowns add to the problem. Hence, the aim of present study was to explore the psychosocial impact of COVID-19 and state imposed lockdown on such caregivers, living with the dilemma of their patient being infected or not, because of the resemblance of the symptoms with COVID-19.

# MATERIALS AND METHODS

This prospective observational study was conducted in the Department of Pulmonary Medicine, Government Medical College, Patiala, Punjab, India (tertiary care institute), from April 2020 to June 2020. The study was approved by the Institute's Research and Ethics Committee {(Trg)EC/NEW/.INST/2020/997/4407}. Informed consent was taken from all participants.

**Inclusion criteria:** All the caregivers of patients, presenting with respiratory complaints which could be mimicking COVID-19 (like cough, fever, shortness of breath, nasal congestion, sore throat, generalised weakness) and were more that 18 years of age were included in the study.

**Exclusion criteria:** Caregivers having any respiratory complaint, underlying respiratory disease or psychiatric illness, were less than 14 years of age, had lack of competency in completing the questionnaires, had evident memory deficits on clinical assessment, had lack of capacity or had organicity (delirium, dementia) were excluded from the study.

Total 65 caregivers who presented to the Outpatient Department for treatment of their patients were enrolled into the study by convenience sampling, due to limitations in availability of study population during the period of strict lockdown.

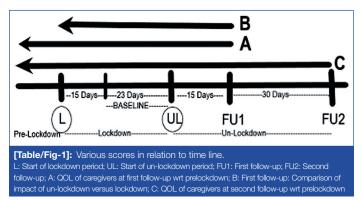
## Assessment

Assessment was done at three points of time.

Baseline: The caregivers were assessed at baseline, in person, during strict lockdown (7th April, 2020 to 29th April 2020) and

First follow-up: At follow-up from 11th to 15th day after the strict lockdown was eased (10th to 14th May, 2020).

Second follow-up: The third assessment was done from  $9^{th}$  to  $13^{th}$  June, 2020, after about 41-45 days of the first relaxation in lockdown [Table/Fig-1].



The follow-up assessments were either in person or through telephonic interviews. At the third assessment, only the overall QOL at that point of time was compared with the prelockdown phase on a scale ranging from -10 to +10.

### Procedure

**Study tools:** The study tools consisted of a proforma containing socio-demographic characteristics, COVID-19 and lockdown related questions, GHQ-12 and quality of life.

Baseline assessment was done using the following instruments:

- 1. Socio-demographic proforma: A structured proforma was used to record the data like age, gender, occupation, residence, family related information etc.
- COVID-19 related questionnaire: All caregivers were asked if 2 they felt the symptoms of their patients are because of COVID-19 or they are worried for COVID-19. Those answering 'yes' to any of these two questions were administered Visual Analogue Scale (VAS), ranging from 0 to 10, for evaluating their extent of worry [30]. Those who scored more than zero on VAS were asked the eight questions related to frequency of anxiety, nervousness, depression, loneliness, stigma, sleep disturbances, thoughts of death, need for addictive substances and thoughts of hopefulness for future during the last one week. It was a self structured questionnaire devised by the authors and administered by the interviewer. The questions were taken and adapted from literature [31]. They were then subjected to extensive review by three experts to add to face validity. VAS was not administered to those answering 'no' to both the questions, as it was a 0-10 scale to gauge the extent of a positive response.

The answers were noted as rarely or none of the time/ some or a little of the time/occasionally or a moderate amount of time and most or all of the time and scored as 0,2,4 and 6 respectively.

Addition of scores of all these answers was taken as the Total score (COVID-19). This total score (COVID-19) was the sum of scores of each of the eight questions, with minimum score being zero and maximum being 48. The scores were taken as absolute values thus obtained after addition of answers of eight questions.

### 3. Lockdown related questionnaire

All caregivers were assessed on three domains for the impact of lockdown on day to day living.

- Domain 1 dealt with difficulties in approaching medical care and assess to daily needs due to strict administrative measures and questions were asked as: delay in seeking medical care, availability of doctors at local level, availability of medications at local level, managing travel to hospital due to administrative reasons and availability of daily needs.
- Domain 2 asked questions dealing with financial condition like: bearing the cost of medications, bearing the cost of travel to the hospital, threat to future financial situation and expenditure on items of daily living.
- Domain 3 assessed psychological aspects with queries on: threat to day to day routine, experiencing social isolation, threat to integration with family due to excessive use of gadgets, threat to professional life/employment and if feel like escaping from the guarded surroundings.

Domain 1 and 3 had 5 questions each and Domain 2 had four questions. Each patient was rated as facing 'none', 'minor' and 'major' difficulty and scored as 0, 2 and 4 respectively. Addition of scores of the three domains was taken as Total score (lockdown). Total score of each domain was the sum of scores of all the questions. Thus, Domain 1 and three could have a maximum score of 20 while domain 2 could have a maximum score of 16. Minimum score of any of the 3 domains was zero. Scores were analysed and interpreted as absolute values of individual domains and as total score (lockdown).

Predominant thought process was noted as positive if the patient reported that he was hopeful that the situation will normalise in next few weeks. It was noted as negative if the patient felt that the situation will worsen/stay the same. COVID-19 related questionnaire and lockdown related questionnaire were carefully designed self structured questionnaires devised by the authors. They were subjected to extensive review by three experts to add to face validity. However, they could not be subjected to proper assessment of the psychometric properties because of time constraints and situation arising out of the pandemic. Reliability exercise could not be carried out.

4. General Health Questionnaire-12-Hindi version (GHQ-12): It is a 12-item screening instrument commonly used for measuring psychological distress and is validated in the Indian population. It was administered to evaluate the impact of lockdown on mental health. Any caregiver scoring ≥3 was defined as a case with psychological morbidity [32].

All the above four listed instruments were administered. Those caregivers scoring GHQ-12 score  $\geq$ 3 at baseline were considered as experiencing psychological distress and counseled by the pulmonologist. At first follow-up assessment, those with a GHQ-12 score of  $\geq$ 3 were deemed to be suffering from psychological distress and additionally advised to consult a Psychiatrist.

In addition, overall quality of life (QOL) at first follow-up (after relaxation of lockdown) was compared with the prelockdown phase on a scale of -10 to +10 (Score A). QOL before lockdown was scored as 10. If the patient reported his present QOL to be even poorer than his prelockdown QOL, he was scored on a Likert scale as a negative score (0 to -10). If his QOL seemed reaching the prelockdown score of 10, he was scored on a Likert scale as a positive score (0 to +10). The caregivers were also studied for the impact of relaxation of lockdown on their QOL (day to day living) vs the lockdown phase on a scale ranging from -10 to +10 (Score B). At second follow-up, only the overall QOL at that point of time was compared with the prelockdown phase on a scale ranging from -10 to +10 (Score C) [Table/Fig-1]. Score C was calculated similar to Score A, with prelockdown score for each caregiver being taken as 10 for uniformity at baseline.

Data collection was done by one to one interviews and administration of the questionnaires and study tools, in person, by the clinician.

# **STATISTICAL ANALYSIS**

Categorical variables were reported as counts and percentages. Group (GHQ-12<3/GHQ-12≥3) comparisons were made with Chi-Square test or Fisher's exact test, as deemed appropriate. Normality of quantitative data was checked by measures of Kolmogorov-Smirnov tests of Normality. Since the data was non normally distributed (skewed), hence values were given as mean±SD, range, median and inter-quartile range. For data, based on the basis of different groups (GHQ-12<3 /GHQ-12≥3), comparison was made by Mann-Whitney U test. Spearman correlation coefficient was calculated to see relation of different variables (quantitative data). For time related variables of skewed data, Wilcoxon Signed rank test was applied and McNemar's test was applied for comparison between categorical values of different timings. The factors which came out to be significant in Bivariate analysis by Chi-square test/ Fisher's exact test or Mann-Whitney U test were put to Bivariate Logistic Regression analysis. Analysis was conducted using Statistical Package for Social Sciences (IBM, SPSS) version 22.0. A p-value <0.05 was considered as statistical significant.

# RESULTS

Total 65 caregivers were enrolled in the study. Five participants were lost to follow-up. Hence, 60 caregivers were finally analysed. At first follow-up, 24 caregivers were interviewed in person, remaining 36 caregivers were telephonically interviewed. At second follow-up, all the caregivers were interviewed telephonically.

Mean age of the participants was  $40.2\pm11.812$  years with maximum caregivers 25 (41.7%) aged between 31-40 years. Majority of the caregivers 50 (83.3%) were males and 52 (86.7%) were employed. Majority of the caregivers 52 (86.7%) were not suffering from co-morbidities [Table/Fig-2].

At baseline and at first follow-up, 30 (50%) and 16 (73.3%) caregivers had a GHQ-12  $\geq$ 3, and hence were experiencing psychological distress respectively. At first follow-up, significantly lesser number of caregivers 17 (28.3%) were worried for COVID-19 (p-value=0.035). Significantly lesser number of caregivers 16 (73.3%) experienced psychological distress at first follow-up (GHQ  $\geq$ 3) (p-value=0.001). There was a statistically significant improvement in Domain 1, 2 and 3 scores and total score (lockdown related questionnaire) (p-value <0.001, 0.003, 0.001 and <0.001 respectively) [Table/Fig-3].

The association of psychological distress at baseline and at followup with various parameters/ scoring systems was done to see if disturbances in any of these parameters/scoring systems can be indicative of the psychological distress and thus alert the physician, and is depicted in [Table/Fig-4]. At baseline, psychological distress was higher in those who were worried for COVID-19, had poorer domain 1, 2 and 3 scores, total score (lockdown) and total score (COVID-19) (p-value=0.018, 0.005, <0.001, <0.001, <0.001 and 0.010 respectively). At first follow-up, it was significantly higher in those worried for COVID-19, who had negative thoughts, poorer baseline domain 1, 2 and 3 scores, poorer baseline total score (lockdown), poorer follow-up domain 1, 2 and 3 scores, poorer follow-up total

| Variables                         |             | n, %       | Variables  |                | n, %       |  |
|-----------------------------------|-------------|------------|--|----------------|------------|--|
|                                   | ≤20 years   | 3 (5.0%)   | Co-morbidities                                   | Yes            | 8 (13.3%)  |  |
|                                   | 21-30 years | 11 (18.3%) |  | No             | 52 (86.7%) |  |
| A = -                             | 31-40 years | 25 (41.7%) | Addiction (Tobacco/<br>alcohol/other substances) | Yes            | 8 (13.3%)  |  |
| Age                               | 41-50 years | 11 (18.3%) |  | No             | 52 (86.7%) |  |
|                                   | 51-60 years | 6 (10.0%)  | Self income (in rupees)                          | Nil            | 10 (16.7%) |  |
|                                   | >60 years   | 4 (6.7%)   |  | <5000          | 3 (5.0%)   |  |
| Gender                            | Female      | 10 (16.7%) |  | 5001-10,000    | 26 (43.3%) |  |
|                                   | Male        | 50 (83.3%) |  | 10,001-20,000  | 12 (20.0%) |  |
| Locality                          | Rural       | 25 (41.7%) |  | 20,001-50,000  | 5 (8.3%)   |  |
|                                   | Urban       | 35 (58.3%) |  | >50,000        | 4 (6.7%)   |  |
| Education<br>(standard)           | <10         | 24 (40.0%) | Occupation                                       | Government job | 6 (10.0%)  |  |
|                                   | 10-12       | 27 (45.0%) |  | Labourer       | 9 (15.0%)  |  |
|                                   | >12         | 9 (15.0%)  |  | Private job    | 15 (25.0%) |  |
| Number of people per<br>household | 1-4         | 23 (38.3%) |  | Student        | 3 (5.0%)   |  |
|                                   | 5-6         | 26 (43.3%) |  | Self-employed  | 19 (31.7%) |  |
|                                   | >6          | 11 (18.3%) |  | Unemployed     | 8 (13.3%)  |  |

[Table/Fig-2]: Socio-demographic profile of study participants (n=60).

| Variables  |               | Baseline              | First follow-<br>up | p-value   |  |
|--|---------------|-----------------------|---------------------|-----------|--|
| Attribute  | Yes           | 2 (3.3%)              | 1 (1.7%)            | 1.000     |  |
| symptomatology to<br>COVID-19  | No            | 58 (96.7%)            | 59 (98.3%)          |           |  |
|  | Yes           | 26 (43.3%)            | 17 (28.3%)          | 0.025     |  |
| Worry for COVID-19   | No            | 34 (56.7%)            | 43 (71.7%)          | 0.035     |  |
| Predominant thought  | Positive      | 29 (48.3%)            | 32 (53.3%)          | 0.004     |  |
| process  | Negative      | 31 (51.7%)            | 28 (46.7%)          | 0.664     |  |
|  | ≥3            | 30 (50%)              | 16 (26.6%)          | 0.001     |  |
| GHQ-12   | <3            | 30 (50%)              | 44 (71.6%)          | 0.001     |  |
|  | М             | lean scores           |                     |           |  |
| Domain 1 score   |               | 9.73±4.317            | 2.03±2.864          | <0.001    |  |
| Domain 2 score   |               | 7.80±5.605            | 5.73±6.075          | 0.003     |  |
| Domain 3 score   |               | 6.97±4.254            | 4.52±4.463          | 0.001     |  |
| Total score (lockdown related questionnaire)   |               | 24.5±11.269           | 12.28±11.646        | <0.001    |  |
| Mean VAS score   |               | 5.3214±3.196          | 5.653±3.0849        | 0.975     |  |
| Total score (COVID-19 related questionniare)   |               | 4.12±6.020            | 2.94±5.202          | 0.316     |  |
| [Table/Fig-3]: Psycholo<br>at first follow-up.<br>COVID-19: Corona virus dise<br>questionnaire-12-hindi versio | ease 2019; VA | S: Visual analogue sc | ore; GHQ-12: Gener  | al health |  |

score (lockdown), and poorer scores A, B and C (p-value <0.001, 0.001, 0.028, 0.025, 0.010, 0.002, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.001, <0.

## DISCUSSION

In the Indian subcontinent, family as a unit plays an integral part of the society. Because of strong familial and societal ties, caregivers play a substantial role in the management of their patients. Their psychological makeup, is very important for the well being of their patients.

Majority of the caregivers in the present study were males, reflecting the gender bias. In the male dominated Indian society, it is believed that males can handle problems better than females. A similar study in the past had all the female participants, as it was conducted on nurses as caregivers [23]. Majority (86.7%) of the caregivers were employed, and representative of the financial heads of their families. In a similar previous study, 54.8% of the caregivers were employed [26].

Caregivers were enrolled after 15 days of announcement of lockdown. Due to travel restrictions, none of the caregivers was a COVID-19 suspect [6]. Two caregivers felt the symptoms of their patients to be because of COVID-19. Twenty six caregivers were worried for COVID-19. Majority of our caregivers resided nearby, and hence approached us in-person. But many reported a difficulty in reaching the hospital. A few caregivers even requested for financial and travel related support and for a follow-up visit at a later date than advised.

Though all the caregivers were completely asymptomatic and apparently healthy, 50% were experiencing psychological distress. The ongoing pandemic, strict lockdown and its associates were the reasons. The present study results are similar to the caregiver

|   | Baseline (n=30) |                          | First follow-up (n=16) |                          |
|---|-----------------|--------------------------|------------------------|--------------------------|
| Variables   | p-value         | Value (statistical test) | p-value                | Value (statistical test) |
| Attribute symptomatology to COVID-19              | 0.492 (NS)      | 2.069 (C)                | 1.000 (NS)             | 0.752 (F)                |
| Worry for COVID-19                                | 0.018*          | 6.787* (C)               | 0.071 (NS)             | 3.264 (C)                |
| Predominant thought process                       | 0.071 (NS)      | 3.270 (C)                | 0.668 (NS)             | 0.184 (C)                |
| Expectations from the physician                   | 0.623 (NS)      | 2.623 (C)                | 0.408 (NS)             | 3.983 (C)                |
| Attribute symptomatology to COVID-19 at follow-up | -               | -                        | 0.267 (NS)             | 2.797 (F)                |
| Worry for COVID-19 at follow-up                   | -               | -                        | <0.001*                | 12.543*** (C)            |
| Follow-up predominant thought process             | -               | -                        | 0.001*                 | 10.484*** (C)            |
| Baseline domain 1 score                           | 0.005*          | 261.0 *** (MW)           | 0.028*                 | 222.000* (MW)            |
| Baseline domain 2 score                           | <0.001*         | 165.5*** (MW)            | 0.025*                 | 219.000* (MW)            |
| Baseline domain 3 score                           | <0.001*         | 146.0*** (MW)            | 0.010*                 | 202.000* (MW)            |
| Baseline total score (lockdown)                   | <0.001*         | 112.5*** (MW)            | 0.002*                 | 168.000*** (MW)          |
| Baseline total score (COVID-19)                   | 0.010*          | 31.000* (MW)             | 0.578                  | 29.500 (MW)              |
| Baseline VAS score                                | 0.099 (NS)      | 42.500 (MW)              | 0.203 (NS)             | 56.000 (MW)              |
| Follow-up domain 1 score                          | -               | -                        | <0.001*                | 151.500*** (MW)          |
| Follow-up domain 2 score                          | -               | -                        | <0.001*                | 136.000*** (MW)          |
| Follow-up domain 3 score                          | -               | -                        | <0.001*                | 124.500*** (MW)          |
| Follow-up total score (lockdown)                  | -               | -                        | <0.001*                | 113.000*** (MW)          |
| Follow-up total score (COVID-19)                  | -               | -                        | 1.000                  | 35.000 (MW)              |
| Follow-up VAS score                               | -               | -                        | 0.115 (NS)             | 19.000 (MW)              |
| Score A   | -               | -                        | <0.001*                | 134.000*** (MW)          |
| Score B   | -               | -                        | <0.001*                | 143.000*** (MW)          |
| Score C   | -               | -                        | <0.001*                | 149.000*** (MW)          |

first follow-up (n=16).

COVID-19: Corona virus disease 2019; VAS: Visual analogue score; GHQ-12: General health questionnaire-12-hindi version; C: Chi-square test; F: Fisher's exact test; MW: Mann-Whitney U test; p-value <0.05 was considered as statistical significant

Mean A. B and C scores were  $4.42\pm3.03$ ,  $5.59\pm4.07$  and  $6.94\pm2.74$  respectively. Mean C score was significantly better than A score (p-value <0.001). Mean C scores were poorer in those with psychological distress at baseline and follow-up (p-value=0.001). C scores significantly and positively correlated with score A.

psychological burden as reported in the past, where psychological burden of 42.3% in short-term caregivers and 46.5% in long-term caregivers was identified [27]. Another study found 79.4% of the children to be psychologically disturbed due to lockdown [25]. Other studies also reported similar results [23,26,33].

Caregivers felt difficulty in access to medical care for their patients and tried postponing it. Local practitioners were not available and medical shops, were closed. There was difficulty in procuring items of day to day use due to limited timings. This resulted in poorer domain 1 scores, which improved significantly with relaxation in lockdown, but were still far from normal.

Assessment on domain 2 showed that financial issues were faced by almost every participant, except those in regular Government jobs. There was near complete closure of work and no means of livelihood. Some people lost their jobs and exhausted their savings while others had to bear major salary cuts because of impending economic recession. The labor class and daily wagers were unable to purchase essential food items and were left at the mercy of others for feeding their families. The score immediately improved with relaxation in lockdown. With the slow and gradual resumption of work and business, people felt hopeful and financially secure. Still, the return to normalcy was far from reality.

Domain 3, which dealt with psychological aspects revealed that people were bothered for their employment and professional life, and financial losses arising henceforth. Loss of social circle, increased screen time, and little unauthentic information on social networking sites added to the psychological burden. Though some caregivers felt more integrated and closer to their families than ever before, however, financial insecurity was bothersome. The score improved at follow-up, but did not reach pre-COVID-19 times. The results of the present study are consistent with the issues highlighted by the World Health Organisation [34].

As soon as the lockdown was relaxed, significantly lesser number of caregivers experienced psychological distress (GHQ  $\geq$ 3). There was a 'limited' time bound return of professional and social life, however, return of livelihood to a 'common man' in a developing country like ours emerged as the biggest contributors to mental health in majority, as reflected in the present study results. Similar findings of improvement in mental health on relaxation in lockdown have been reported in the past too, where an improvement in the score of generalised anxiety disorder scale and impact of events scale-revised was noted [35].

At follow-up, significantly lesser number of caregivers were worried for COVID-19, showing adaptive behaviours over a period of time. However, few reported worsening of their thoughts, leading to even poorer mean VAS scores at follow-up than baseline.

Results of total score (lockdown), at baseline and follow-up confirmed the high inter-dependency of the three domains on each other. Correlation of higher psychological distress (at baseline and follow-up) with poorer scores of the different scoring systems shows the need to foresee the impact of lockdown in totality, and use these scoring systems as screening indices for identification and persistence of psychological distress. Its consequences on a common man should be dealt in a comprehensive manner during decision making and formulation of policies at administrative level. Same has been proposed by DA Silva M [36].

At follow-up assessments, the mean B score was higher than the Mean A score. People were adapting themselves to the 'new normal'. Mean C score, hence was even better than score A, however, the scores were still far from the 'real normal' prelockdown scores (taken as a 10). This persistence of psychological distress in some caregivers shows that it may take a long time before reaching back to the pre-COVID-19 era.

The findings of our study regarding the 'apparently healthy' caregivers gains special relevance during preparations of subsequent waves of the pandemic. Varying degrees of lockdown may again be imposed [37]. There were reports of breach in law and order due to distress of the caregivers [38]. Mental healthcare professionals should be actively engaged in identifying such caregivers in 'distress' on priority and help in improving their coping strategies. Caregivers may have to play an equally important role in supporting our overburdened healthcare system for streamlined management of such atrocities in future.

The present study is methodologically sound as it is a longitudinal study, with minimal drop out. Besides, unlike previous studies, questionnaire was not self-administered or online based but administered by a single clinician (KG) throughout the study using face-to-face/telephonic interviews.

### Limitation(s)

Being an Outpatient based study with direct contact with caregivers of patients with respiratory complaints, there was a potential risk of exposure to COVID-19. Hence, a more comprehensive assessment of psychological aspects could not be done. Additionally, the questionnaire used in the present study was not subjected to proper assessment of its psychometric properties due to time constraints.

## CONCLUSION(S)

Psychological distress was experienced in 50% and 23.7% of the 'apparently normal' caregivers at baseline and at follow-up even after post lockdown 'relaxation'. This huge burden of psychological distress, if left unevaluated, would have remained undetected. There is a need for future studies with larger sample size and use of simplified screening tools to detect this psychological distress early so that corrective steps are taken in the initial phases of such pandemics.

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