Original Research Article

An observational study to evaluate psychological experience and social stigmas in COVID-19 patients: a prospective study on home isolated patients

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ABSTRACT

Background: Coronavirus disease 2019 (COVID-19) has caused significant distress. Apart from evident physical symptoms in infected cases, it has caused serious damage to public mental health. The present study was carried out to assess disease burden, fear and stigma associated in home isolated patients.

Methods: A Prospective, observational study of 8 weeks began after IEC approval in diagnosed COVID 19 patients who were home isolated and visited by the researcher as part of Sanjeevni home care service launched by the municipal corporation. Number of patients turning symptomatic from asymptomatic was recorded. Frequency for transmission was also noted. Fear and social stigma by Fear of COVID 19 scale (FCV-19S) and Stigma scale was measured respectively.

Results: A total of 746 patients were included in the study (mean age: 40.2±16.2 years). About 105 patients (14.07%) suffered from co-morbidities like Hypertension, Diabetes, Obesity. About 38.47% were asymptomatic while 61.53% were symptomatic during their home isolation period. Among asymptomatic patients, 48.78% became symptomatic during their period of home isolation and follow up. A family member being found positive was 35.19% from asymptomatic patients while 34.85% from symptomatic patients. The mean score of the patients for fear and stigma in our study was 14.74±5.13 and 35.13±8.48 respectively.

Conclusions: Both symptomatic as well as asymptomatic patients can transmit the disease with equal frequency. Asymptomatic at diagnosis also converts to symptomatic in almost half of the population. This further highlights the importance of home isolation. This was the first time we have used a Stigma and Fear scale in patients affected by COVID 19 who were home isolated. Higher score of Fear scale was seen in >50 years of age.

Keywords: COVID 19, Home isolation, Fear of COVID 19 scale, Stigma scale, Stigmatization

INTRODUCTION

World Health Organization (WHO) declared Coronavirus disease 2019 (COVID-19) a pandemic on 11th March, 2020. The public health strategy in India is focused on 3T strategy – (Tracing, Testing and Treatment), is helping to keep COVID-19 under check.[1] The persons infected by the novel coronavirus are the main source of infection.

Spectrum of clinical manifestations of COVID-19 cases may range widely from being asymptomatic, to moderately symptomatic to having severe cytokine storm culminating in mortality.[1]

The patients who are diagnosed with COVID-19 are either hospitalized or isolated/quarantined in their homes depending upon their clinical symptoms. This study

focused on patients who were home isolated. The health team went to these home isolated patients on a daily basis to evaluate clinical status and vitals of patients like RR, pulse, SpO2 and blood pressure etc. The researcher was a part of this health care team.

With respect to social stigma of COVID-19 patients, there was an incident where a pregnant woman was reportedly abandoned by her family in India, after she gave birth to a child at a hospital in Maharashtra state, and was found positive for SARS-CoV-2. In some cases, COVID-19 survivors in India were stalked on social media. A COVID-19 survivor in Harare, Zimbabwe, got surprised, when the road in front of his house was named as "corona road" and some people even preferred to avoid the road fearing the possibilities of infection. "Social stigma in COVID-19 pandemic is attributable to unscientific belief and improper understanding in common masses", says, a professor of microbiology at the Infectious Diseases and Beliaghata General Hospital (Kolkata, India).[2]

Home isolation brings about anxiety, worries, fear and social disabilities. This home isolation is for 14 days, for self or the family members. Especially in developing countries like ours it is considered as a social stigma since it is a contagious disease and people fear getting identified and stigmatized.

Hence, this study was designed to evaluate sociodemographic and clinical characteristics, fear and social stigma in COVID 19 patients who were home isolated.

METHODS

Study design

A prospective observational study of 8 weeks duration from September 2020 to November 2020 involving diagnosed COVID 19 patients who were home isolated. The study began after the approval of study protocol by the Institutional Ethics committee. Inclusion criteria were all patients who were home isolated for COVID 19 infection and patients who were willing to give informed consent. Patients suffering from psychiatric diseases and were not able to comprehend the questionnaire were excluded. Patients who were hospitalised or in covid care centres were also excluded. Study site were all the localities of Ahmedabad which had access to Sanjeevani home care services.

Sampling techniques

This community based observational study was carried out among the population of urban area of Ahmadabad district, Gujarat. Ahmedabad Municipal Corporation (AMC) has 7 zones and 48 wards. Total 77 urban health centers (UHC) are present in every ward of Ahmadabad city.[14] Now from the selected ward, line listing of all patients who were home isolated for COVID 19 was done with help of UHC

and AMC. Then, data was taken from the patients by simple random sample till required sample size was achieved. Data of 746 patients was collected from different zones of the city. All those patients who were home isolated following Rapid Antigen Test/RT-PCR/HRCT were included in this study after written informed consent. Their clinical and sociodemographic data was recorded. Patient was subjected to two validated and pretested questionnaires related to fear and stigma in their vernacular language. These patients were followed from first day of isolation till 14 days. These patients were visited by the researcher as part of Sanjeevani home care services launched by the Municipal Corporation.

Definitions and instruments used

Definitions

Symptomatic: Case is a person who has developed signs and symptoms compatible with COVID-19 virus infection. Symptoms like fever, weakness, fatigue, cough, loss of taste and loss of smell.

Asymptomatic: Case is a person infected with COVID-19 who does not develop symptom.

Sajeevani home care: "Sanjeevni Van:Corona GharSeva" was started for asymptomatic or mild symptomatic home isolated patients from 6th July 2020. Sanjeevni vans have a team of trained paramedical staff along with either a resident doctor or an undergraduate medical student. They visit the residence of home isolated-patients and check on their medical condition every day till 14 days of testing positive.

Instruments

Fear scale: This scale comprises Seven questions and answers were scored on Likert scale. The minimum score possible for each question is 1 and maximum is 5 (score range 7-35) higher score indicate more fear and lower score indicate less fear .[4]

Stigma scale: This stigma scale was newly developed scale which was Questionnaires based to analyze stigma associated with COVID. It comprises of 13 items each of which is scored on 5 point Likert scale and higher score indicate more stigma.[5] The content validity of the scale was established by the content validity index exceeding 0.78.[5]

Statistical analysis

The complete data was entered in Microsoft Excel 2019 worksheet to check any possible error, and subsequently, statistical analysis was done using Statistical package for social sciences (SPSS) software version 25. For continuous data, normally distribution was checked through kolmogorov-Smirnov test and $p>0.05$ indicated normal distribution of data. Unpaired T-test was used to compare

data between groups for continuous variables. The association between two categorical variables was tested with Fisher's exact test. Symptomatic patients and asymptomatic patients status were assessed by Unpaired T-test. P<0.05 was considered statistically significant.

RESULTS

A total of 746 patients were visited by health personnel. Those patients diagnosed as COVID 19 who were home isolated and fulfilled the inclusion criteria were included.

Table 1: Fear and Stigma scale according to clinical characteristics (n=746).

Parameter	Asymptomatic (n=288)	Symptomatic (n=458)	P value*
Age (in years)	42.71±15.96	38.75±16.16	0.0012*
Male	171	287	0.39
Female	117	171	
Fear	14.88±5.44	14.66±4.94	0.569
Stigma	36.61±9.086	34.20±7.955	0.0001*
Fear scale			
Q1. I am most afraid of Corona	2.32±1.884	3.22±1.990	0.0001*
Q2. It makes me uncomfortable to think about Corona	2.66±1.863	2.42±1.197	0.0325*
Q3. My hands become clammy when I think about Corona	3.28±1.984	2.88±1.998	0.0078*
Q4. I am afraid of losing my life because of Corona	2.50±1.940	2.01±1.741	0.0004*
Q5. When I watch news and stories about Corona on social media, I become nervous or anxious.	1.88±1.656	1.67±1.498	0.0740
Q6. I cannot sleep because I'm worrying about the effects of Corona.	2.86±1.999	3.69±1.879	0.0001*
Q7. My heart races or palpitates when I think about Corona.	2.11±1.795	2.03±1.751	0.547
Stigma Scale			
Q1. Some people think that the relatives of COVID-19 positive people are contaminated.	3.75±1.85	3.23±1.98	0.0004*
Q2. Some people think that the relatives of COVID-19 positive people might infect them.	3.76±1.85	3.82±1.82	0.6633
Q3. Some people do not want their children to associate with the children of the COVID-19 affected families.	3.08±2.00	3.72±1.86	0.0001*
Q4. Some people do not want their family members [roommates]to get close to the family members of the COVID-19 infected individual.	2.28±1.86	2.32±1.88	0.7764
Q5. Some people avoid meeting with friends of the COVID-19 suffering family.	2.53±3.00	1.94±2.00	0.0013*
Q6. Some people try not to get in contact with the COVID-19 affected family.	2.86±1.99	3.69±1.87	0.0001*
Q7. I was hurt when others treated me differently from normal people because I was COVID-19 positive.	2.11±1.79	2.03±1.75	0.5475
Q8. The fact that I am COVID-19 positive, made me differentiate myself from others	2.21±1.84	2.41±1.19	0.0718
Q9. I cautioned my family [parents, spouse or children, etc] not to tell others that they are the family members of a COVID-19 positive person.	2.49±1.93	2.97±2.00	0.0013*
Q10. I do not want to let others know that I am COVID-19 positive.	1.74±1.55	1.72±1.53	0.8627
Q11. I had the unpleasant experience of being discriminated against because I was COVID-19 positive.	2.07±1.77	2.58±1.95	0.0003*
Q12. I am worried about how others will treat my family [parents, spouse, children, etc] just because I am COVID-19 positive.	2.96±2.00	2.61±1.96	0.0187*
Q13. I kept myself away from others because I might spread the COVID-19 virus.	3.26±1.98	3.31±1.97	0.7363

*P value was calculated based on unpaired t test. P value less than 0.05 considered as statistically significant.

Table 2: Fear and stigma scale according to gender.

Parameter	Male (n=458)	Female (n=288)	P value*
Age (in years)	39.56±16.08	41.43±16.32	0.124
Fear	14.36±4.997	15.36±5.309	0.012*
Stigma	34.87±8.241	35.55±8.859	0.302
Fear scale			
Q1. I am most afraid of Corona	2.82±1.994	3.43±1.970	0.0001*
Q2. It makes me uncomfortable to think about Corona	2.37±1.90	2.35±1.89	0.8885
Q3. My hands become clammy when I think about Corona	3.06±2.00	2.99±2.00	0.6418
Q4. I am afraid of losing my life because of Corona	2.19±1.83	2.22±1.84	0.8279
Q5. When I watch news and stories about Corona on social media, I become nervous or anxious.	1.75±1.56	1.75±1.56	1.0000
Q6. I cannot sleep because I'm worrying about the effects of Corona.	2.29±1.87	2.65±1.97	0.0124*
Q7. My heart races or palpitates when I think about Corona.	2.67±1.97	2.90±2.00	0.1232
Stigma Scale			
Q1. Some people think that the relatives of COVID-19 positive people are contaminated.	3.44±1.95	3.42±1.96	0.8918
Q2. Some people think that the relatives of COVID-19 positive people might infect them.	4.11±1.66	3.31±1.98	0.0001*
Q3. Some people do not want their children to associate with the children of the COVID-19 affected families.	3.45±1.95	3.53±1.93	0.5841
Q4. Some people do not want their family members [roommates]to get close to the family members of the COVID-19 infected individual.	2.03±1.75	2.73±1.98	0.0001*
Q5. Some people avoid meeting with friends of the COVID-19 suffering family.	2.72±1.98	2.97±2.00	0.0949
Q6. Some people try not to get in contact with the COVID-19 affected family.	3.38±1.96	3.36±1.97	0.8923
Q7. I was hurt when others treated me differently from normal people because I was COVID-19 positive.	1.86±1.64	2.39±1.90	0.0001*
Q8. The fact that I am COVID-19 positive, made me differentiate myself from others	2.28±1.86	2.40±1.91	0.3962
Q9. I cautioned my family [parents, spouse or children, etc] not to tell others that they are the family members of a COVID-19 positive person.	2.78±1.99	2.78±1.99	1.0000
Q10. I do not want to let others know that I am COVID-19 positive.	1.97±1.71	1.33±1.10	0.0001*
Q11. I had the unpleasant experience of being discriminated against because I was COVID-19 positive.	2.36±1.89	2.42±1.91	0.6743
Q12. I am worried about how others will treat my family [parents, spouse, children ,etc] just because I am COVID-19 positive.	2.33±1.88	3.40±1.96	0.0001*
Q13. I kept myself away from others because I might spread the COVID-19 virus.	3.51±1.93	2.94±2.00	0.0001*

*P value was calculated based on unpaired t test. P value less than 0.05 considered as statistically significant

The total numbers of males affected were 61.39 % (458 male patients). While the total number of females affected were 38.61% (288 female patients). The male: female ratio was 1.59. The mean age of the patients (n=746) in our study was 40.2years (SD±16.2). The highest number of patients were found in the age group of 21-30 years (162 patients), followed by 31-40 years (155 patients), followed by 41-50 (156 patients) while lowest number of patients were found in age group 18-20 years (71 patients), followed by 61-70 years (60 patients), followed by 71-80 years (25 patients) and followed by 81-90 years (7 patients).

Elderly patients aged >60 are to be admitted in hospital as per the guidelines for home isolation issued by the Ministry of Health and Family Welfare. This accounted for a lower number of patients in >60 years category in our study. A total of 104 patients (13.94%) were greater than 60 years of age.

About 105 patients (14.07%) were suffering with co-morbid conditions such as hypertension, diabetes, obesity and other conditions. About 32.38% (34 patients) had hypertension followed by diabetes mellitus in 26.66% (25 patients). There were 33 patients and 72 patients suffering with co-morbidities among the asymptomatic and symptomatic, respectively. Average number of patients

among each household was calculated by dividing the number of patients by the number of household members which was noted as approximately 5.00 per house hold.
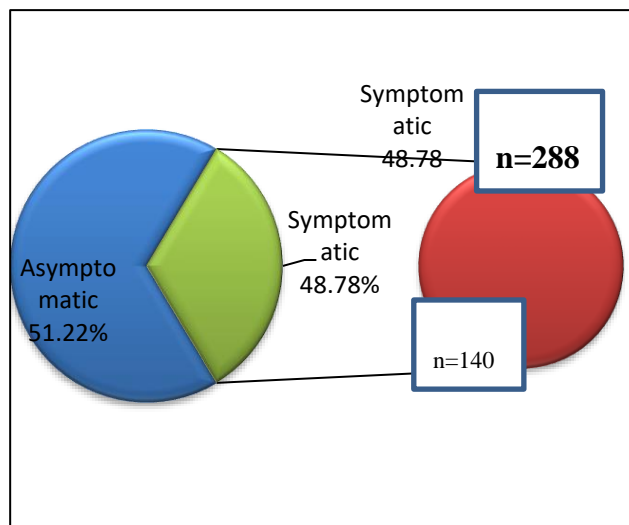

Figure 1: Asymptomatic turning into symptomatic patients (n=288).
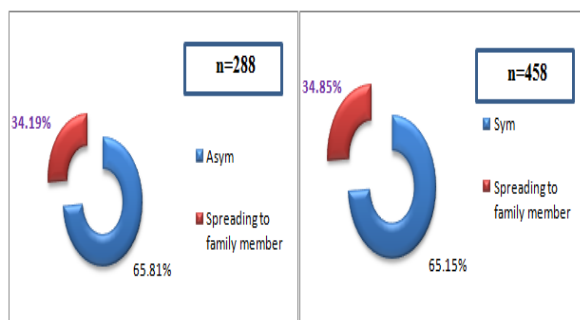

Figure 2: Frequency of family member being positive in asymptomatic or symptomatic patients household.

In our study 38.47% (288 patients) were asymptomatic while 61.53% (458 patients) were symptomatic. The symptomatic: asymptomatic patient's ratio was 1.59. The average age of asymptomatic patient was 42.71years while average age of symptomatic patients was 38.79 years. Out of 598 symptomatic patients 20.06% (120 patients) had fever followed by 19.39% (116 patients) had weakness and others symptoms like cough, headache, diarrhea, loss of smell and loss of taste.

Out of the 288 asymptomatic patients 48.78% (140 patients) became symptomatic during their 14 days home isolation period as shown in figure 1. A family member being found positive was 35.19% from asymptomatic patients while 34.85% from symptomatic patients as shown in figure 2. There was no difference in percentage with respect to passing infection to a family member between asymptomatic and symptomatic patients.

Fear of COVID-19 scale

The mean value of the patients (n=746) for fear in our study was 15.35±5.30. Regarding patients perception of the disease, out of the 746 patients in our study 33.1% (247 patients) disagreed and 31.6% (236 patients) agreed that they were afraid of corona About 20.08% (155 patients) agreed and 7.4% (55patients) strongly agreed, when they watch news and stories about corona on social media they become nervous or anxious. About 43.56% (325 patients) strongly disagreed and 9.91% (74 patients) agree about afraid of losing their life because of corona.

Social stigma scale

The mean value of the patients (n=746) for stigma in our study was 35.54±8.53. Regarding patients perception of the disease, out of the 746 patients in our study 29.9% (223 patients) agreed and 14.9% (111 patients) strongly disagreed about people thinking that the relatives of COVID-19 positive people might infect them followed by 31.2% (233 patients) who strongly disagreed .Only 6.2% (46 patients) strongly agreed about that they did not want to let others know that they are COVID-19 positive .31.63% (236 patients) disagreed and 10.3% (77 patients) strongly agreed about people avoiding meeting with friends of the COVID-19 suffering family.

Table 1 shows the mean difference between asymptomatic and symptomatic patients. The mean values of fear and stigma for asymptomatic were found to be 14.88 and 36.61 respectively. For symptomatic, the mean values for fear and stigma were found to be 14.66 and 34.20 with 4.94 and 7.955. However, no significant difference was observed with respect to fear (F=9.16, p=0.569) among asymptomatic and symptomatic patients.

Table 2 shows the mean differences between males and females. The mean values of fear and stigma for males were found to be 14.36 and 34.87 respectively. For females, the mean values for fear and stigma were found to be 15.36 and 35.55 respectively. The mean values of females were found to be higher than males. However, significant difference was observed with respect to fear (t=0.75, p=0.012). Males and females did not differ significantly on stigma (t=1.0, p=0.302). Both males and females reported mild fear and moderate stigma. There was statistically significant difference in age (p= 0.0012) and experience stigma (p=0.001) between asymptomatic and symptomatic patient. As far as gender differences were concerned significant difference was (p=0.012) observed with respect to experiencing fear. Female were more fearful of the disease as compared to their male counterparts.

DISCUSSION

The COVID 19 pandemic has had a significant impact on public health.[13] The data in our study was collected over a 2 month period from patients who were home isolated for

COVID 19. This study is one of the first attempts to explore COVID-19 related fear and stigma among home isolated patients using a Fear and stigma-specific tool and to assess its associated factors. Our preliminary findings suggest that most patients experienced some level of COVID-19-related fear and stigmatization.

This study included 746 COVID-19 patients with or without mild symptoms who were quarantined at home. Majority were symptomatic. Male predominance is seen over the female. Fever was the most common symptom followed by generalized weakness, this finding is similar to what is reported in severe symptomatic patients also.[7]

The present study utilized new scales which were the Fear of COVID-19 Scale (FC-19S) and Stigma Scale. The fear and Stigma associated in COVID 19 was substantial. Age and Gender appeared to affect the response pattern of fear and stigma between asymptomatic and symptomatic patients.

Greater fear of COVID-19 among women was observed in our study and similar findings was also observed in other countries such as Israel (Bitan et al, 2020), Eastern Europe (Reznik et al, 2020) and Bangladesh (Sakib et al, 2020). Females generally show greater stress responsiveness than men, which is consistent with the greater incidence of some psychological disorders in women.[11] Our study also revealed that women were more fearful as compared to men (15.36±5.309).

The fear developed in connection with COVID-19 has come to the forefront as an important pressure tool on depressive symptoms, anxiety and stress, which forms a part of psychological adjustment skills. The pandemic with its traumatic nature is likely to affect healthcare professionals and the adverse conditions they face in patients, both as an individual and as a professional stated that the pandemic process should be considered as a traumatic difficult life process.[8] In this sample of home isolated patients, our preliminary findings also suggested that most patients experienced some level of COVID-19 related fear and stigmatization.

Disease-related stigmatization was previously reported for the Acquired Immunodeficiency Syndrome, the Middle East Respiratory Syndrome, and SARS. Similarly, the current COVID-19 pandemic may have led to stigmatizing experiences and practices, such as social exclusion, discrimination, self-blaming and shame. In this exploratory study, approximately half of the patients reported a greater level of COVID-19 related stigma. During previous respiratory disease epidemics, such as the 2004 SARS epidemic, 22% of the studied health care workers (HCW) reported stigma and rejection in their neighbourhood. A similar proportion of patients in this study experienced discrimination from their neighbours.[9,10] This stigmatization of COVID 19 positive patients occurred irrespective of their age. Due to this

reason, patients did not prefer to disclose their positive status.

Because of the ambiguity around COVID-19 and its evolving nature several false beliefs and myths might arise in the community and be propagated by the media, especially with the 'infodemic' associated with the COVID-19 pandemic. Approximately one-thirds of patients thought that media had a negative role in increasing COVID-19 public stigma in agreement with other reports. Participants in this study perceived higher stigma related to the concern with public attitudes.

The results also found that fear of COVID-19 infection is higher in age >50 years. This finding is different from Brazilian study which reported that fear of COVID-19 infection is lower in older participants. Many aspects of the pandemic (quarantine, social isolation, economic situation, among others) can cause high levels of anxiety and, specifically, fear of being infected. The possibility of testing positive for COVID-19 increases the fear associated with the infection and can worsen post-traumatic stress disorders and anxiety.[11]

In a study, on patients of leprosy which is another stigmatized disease, fears consequently cause leprosy patients to isolate themselves to avoid mistreatment and rejection. The beliefs associated with leprosy are complex due to the history of the disease. As the disease has been present in human history for centuries, strong stigmatizing beliefs, which have caused violent situations, have been ingrained in the records of various socio-cultural groups.[12]

The petition had also claimed that people have started skipping the corona tests to shield themselves from the "public embarrassment and stigmatization" which is also caused by pasting posters outside homes of COVID 19 positive patients. The Supreme Court in December 2020 told states and union Territories that they are not required to put up such signages unless ordered by the competent authority under the Disaster Management Act, 2005.[4]

Strength and limitations

This study is one of the first endeavors to measure COVID-19-related fear and stigma among COVID 19 patients during their home isolation period. It also examined various aspects of COVID-19-related stigma. This exploratory study highlights the need for specific research and targeted interventions particularly addressing COVID19-related fear and stigmatization among quarantine patients. Some limitations may prevent the generalizability of these results. First, due to the lack of a specific tool to measure COVID-19-related stigma and fear, we had to use a scale designed to measure other health-related stigma. Verma et al. adapted a stigma scale, which was originally developed to measure HIV-related stigma, to measure post-SARS stigmatization among HCWs. Secondly, the studied patients were from the general population and no formal diagnoses on mood

disorders were obtained (example- anxiety). Therefore, the sensitivity and specificity of the scale cannot be examined.

CONCLUSION

The present study provides important information about Clinical characteristics of Home isolated patients. About half of the asymptomatic patients became symptomatic during their 14 days home isolation period. About 1/3 family member being found positive was from asymptomatic or symptomatic patients. There was no difference in percentage with respect to Frequency of family member being positive between asymptomatic and symptomatic patients. Higher score of Fear scale was seen in > 50 years of age. This was the first time we had used stigma scale and a Fear scale in patients affected by COVID 19 infection who were home isolated. The present study provides important information on the fear and stigma profiles in the home isolated patients. A considerable proportion of home isolated patients experienced COVID-19-related stigmatization, mainly from their neighbours and others they interacted with in the community during the COVID-19 pandemic. Thus, public health education and raising community and media awareness about the importance of public support are necessary to alleviate their perceived stigma. The overall COVID-19-related fear and stigma highlights the need for providing targeted psychological support for home isolated patients.

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