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Stigma among recovered patients of COVID-19 after discharge from a COVID dedicated centre

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Abstract

Aim: To explore the relation of stigma with the socio-demographic profile of the patients who have recovered from COVID.

Methods: 100 consecutive, consenting cases each testing positive (N=50) and Negative (N=50) of age more than 16 years from both the genders will be recruited for the study. Patients were contacted telephonically. The data were collected in the semi-structured Performa and the “Explanatory Model Interview Catalogue (EMIC) stigma scale for affected people”. Keeping in view of the ethical considerations - the patients reporting psychiatric symptoms will also be advised appropriate treatment measures according to recent telemedicine guidelines as per by the National Medical Council.

Results: Out of the 118 selected samples, who were asked to participate in the study, total 100 patients participated in this study. Out of 100, 50 COVID test positive and 50 COVID test negative patients were included in this study. Out of 50 cases 62% of survivors were in the age group of 20-40 years, and close to two-thirds 64% were males, 56% of survivors were from the urban background. The mean time from hospital discharge to study entry was 12.1 ± 4.8 [Range(R) = 6–20] days. 95% of survivors provided at least one stigma endorsing response and the total mean stigma score was 30.5 ± 6.5 (R = 5–40). The mean stigma sub-scores were 8.1 ± 1.6 (R = 2–8) for enacted stigma, 14.7 ± 3.7 (R = 1–22) for externalized stigma and 3.7 ± 2.5 (R = 0–6) for internalized stigma. The mean disclosure concern subscale score was 3.1 ± 1.6 (R = 0–6). Enacted stigma was more among males as compared to females and was statistically significant ($p=0.032$). Enacted stigma and internalized stigma were both associated with education. Enacted stigma ($p<0.001$), externalized stigma ($p = 0.005$), disclosure concerns ($p = 0.001$) and total stigma ($p=0.007$) was significantly associated with occupation of the survivors. After adjusting for age, gender, marital status, and time since discharge, COVID-19 survivors who were farmers [$\beta = -8.55$, 95% CI: -13.61 to -2.32-, $p=0.005$], were less likely to experience stigma as compared to unemployed. Stigma significantly decreased with increasing time since discharge after adjusting for age, gender, marital status, and occupation. [$\beta = -0.76$, 95% CI: -0.83 to -0.45, $p<0.001$].

Conclusion: The high levels of enacted and externalized stigma among COVID-19 test positive survivors.

Keywords: COVID-19, social stigma, socio-demography

Introduction

On 11 March 2020, the World Health Organization (WHO) designated the coronavirus disease 2019 (COVID-19) outbreak a pandemic [1]. As of May 30th; there were more than six million confirmed cases, more than 366,000 deaths, and more than two million recovered cases globally [2]. COVID-19 symptoms include general symptoms such as fever, chills, and malaise; respiratory symptoms such as cough, breathing difficulties and coryza; gastrointestinal symptoms such as vomiting and diarrhoea; and neurological symptoms such as headache and giddiness [3]. Some COVID-19 patients reported olfactory and taste disturbances [4].

Diverse degrees of psychological suffering were identified in different groups of persons as a result of vicarious traumatization from COVID-19, ranging from the general public [5], to mental patients [6], those under quarantine [7], and healthcare personnel [8]. However, research on the neuropsychiatric sequelae and psychological effect of COVID-19 patients is still sparse, with one study finding that the majority of clinically stable individuals had severe posttraumatic stress disorder (PTSD) symptoms [9]. COVID-19 patients' emotional and psychological requirements may differ significantly from those of persons with pre-existing mental disorders and people in the community. Stigma is defined as negative attitudes and ideas that denigrate a person or group of people, resulting in prejudice, societal exclusion, discrimination, marginalisation and racism [10].

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As a result, stigma can result in experiences and sentiments of guilt, humiliation, worthlessness, isolation, social exclusion, and discrimination when it comes to obtaining social amenities and healthcare services [11, 12]. Enacted stigma refers to socially unacceptable expressions such as prejudice and discrimination directed towards people with the stigmatising qualities, whereas internalised stigma refers to the feelings of shame, guilt, or worthlessness experienced as a result of having the stigmatising feature [13].

Since March 2020, most of the Medical College hospitals were classified as a COVID specialized hospitals and many have solely treated COVID cases since then. To prevent the transmission of infection, all suspected cases of COVID are admitted to the hospital and a nasopharyngeal swab is obtained from them, according to the official local guidelines. The collected swab is then tested for RT-PCR at government approved laboratories. The findings are available in 24 to 36 hours. Those that test negative are released as soon as the results are available.

Initially, the positive patients were kept in the hospital until two of their samples came back negative. Following a modification in rules, positive individuals were maintained in the hospital for at least 10 days, with at least one of their samples testing negative. During their stay, patients are separated from other patients and visitors are not permitted. For obvious reasons, the period of hospitalization is stressful for the patients. Another source of anxiety is the unknown nature of the treatment's result and prognosis. The patients are unable to attend to their social contacts at this time and their quality of life is likely to suffer following discharge. When the patient returns to the society, the stigma of having been infected with COVID in the recent past follows them.

Material and Methods

This cross-sectional study was carried out, after taking the approval of the protocol review committee and institutional ethics committee. Informed consent, detailed history was taken from the patient or the relatives if the patient was not in good condition.

Design of the study: This study was cross-sectional one where the consenting patients were interviewed telephonically by a trained investigator.

Sample size: 100 consecutive, consenting cases each testing positive (N=50) and Negative (N=50) of age more than 16 years from both the genders recruited for the study.

Inclusion criteria

- The patients admitted for at least twenty four hours for diagnostic purposes.
- The patients undergoing diagnosis of COVID-19 done using RT-PCR testing of the Naso-pharyngeal swab.
- Those who have completed at least one week in the community/family after discharge.

Exclusion criteria

- Non consenting patients

- Mentally retarded/ severely ill/ not amenable for interviewing

Tools and scales

The following tools will be utilized to assess the patients.

- Explanatory Model Interview Catalogue (EMIC) stigma scale for affected people¹⁴
- Semi-structured data sheet for assessment of socio-demographic profile (Age, gender, Occupation, Place of residence, Socioeconomic status etc).
- Semi structured Performa for assessment of Co-morbid medical illness(s) and important blood or radiological parameters which was deviant from normalcy.

Procedure

All the consenting patients admitted was contacted telephonically (to avoid direct contact and prevent community spread of infection). The data were collected in the semi-structured performa and the "Explanatory Model Interview Catalogue (EMIC) stigma scale for affected people".

Results

Out of the 118 survivors who were asked to participate in the study, total 100 patients participated in this study. 18 patients were excluded from this study. Out of 100, 50 COVID test positive and 50 COVID test negative patients were included in this study. Out of 50 cases 62% of survivors were in the age group of 20-40 years, and close to two-thirds 64% were males, 56% of survivors were from the urban background. The mean time from hospital discharge to study entry was 12.1±4.8 [Range(R) = 6–20] days. 95% of survivors provided at least one stigma endorsing response and the total mean stigma score was 30.5±6.5 (R = 5–40). The mean stigma sub-scores were 8.1±1.6 (R = 2–8) for enacted stigma, 14.7±3.7 (R = 1–22) for externalized stigma and 3.7± 2.5 (R = 0–6) for internalized stigma. The mean disclosure concern subscale score was 3.1±1.6 (R = 0–6) as shown in Table 3. Table 4 summarizes the comparison of externalized stigma, internalized stigma, enacted stigma, disclosure concerns, and total stigma, with socio-demographic variables among COVID-19 survivors. Enacted stigma was more among males as compared to females and was statistically significant (p=0.032). Enacted stigma and internalized stigma were both associated with education. Enacted stigma (p<0.001), externalized stigma (p = 0.005), disclosure concerns (p = 0.001) and total stigma (p=0.007) was significantly associated with occupation of the survivors. After adjusting for age, gender, marital status, and time since discharge, COVID-19 survivors who were farmers [β = -8.55, 95% CI: -13.61 to -2.32-, p = 0.005], were less likely to experience stigma as compared to unemployed. Stigma significantly decreased with increasing time since discharge after adjusting for age, gender, marital status, and occupation. [β = -0.76, 95% CI: -0.83 to -0.45, p<0.001].

Table 1: Socio-demographic profile of the patient

Gender	COVID test positive patients		COVID test negative patients	
	Number	Percentage	Number	Percentage
Male	32	64	30	60
Female	18	36	20	40
Age in years				
20-30	21	42	22	44
30-40	11	22	10	20
40-50	11	22	10	20
Above 50	7	14	8	16
Education				
Illiterate	4	8	5	10
Primary	14	24	12	24
Secondary	8	16	10	20
Tertiary	24	48	23	46
Employment				
employed	19	38	20	40
unemployed	31	62	30	30
Area				
Urban	28	56	27	54
Rural	22	44	23	46
Marital status				
Married	38	76	40	80
Unmarried	12	24	10	20
Travel history	2	4	1	2
Co-morbid medical illness	9	18	10	20
Currently ill?	10	20	12	24

Table 2: EMIC Affected persons responses to various questions

No	Question	COVID test positive patients			COVID test negative patients				
		Yes	Possibly	uncertain	No	Yes	Possibly	uncertain	No
1	If possible, would you prefer to keep people from knowing about your COVID-19?	22	20	nil	8	nil	nil	nil	50
2	Have you discussed your COVID-19 with the person you consider closest to you, the one whom you usually feel you can talk to most easily?	14	12	nil	24	nil	nil	nil	50
3	Do you think less of yourself because of your COVID-19? Has it reduced your pride or self-respect?	6	1	nil	43	nil	nil	nil	50
4	Have you ever been made to feel ashamed or embarrassed because of your COVID-19?	1	nil	nil	49	nil	nil	nil	50
5	Do your neighbours, colleagues or others in your community have less respect for you because of your COVID-19?	4	nil	nil	46	nil	nil	nil	50
6	Do you think that contact with you might have any bad effects on others around you even after you have been treated?	nil	2	nil	48	nil	nil	nil	50
7	Do you feel others have avoided you because of your COVID-19?	18	3	nil	29	nil	nil	nil	50
8	Would some people refuse to visit your home because of this condition even after you have been treated?	10	3	nil	37	nil	nil	nil	50
9	If they knew about it would your neighbours, colleagues or others in your community think less of your family because of your COVID-19?	1	nil	nil	49	nil	nil	nil	50
10	Do you feel that your COVID-19 might cause social problems for your children in the community?	Nil	nil	nil	50	nil	nil	nil	50
11A	Do you feel that this disease might make it difficult for you to marry? (Unmarried)	nil	nil	nil	50	nil	nil	nil	50
11B	Do you feel that this disease has caused problems in your marriage?	nil	nil	nil	50	nil	nil	nil	50
12	Do you feel that your COVID-19 makes it difficult for someone else in your family to marry?	1	nil	nil	49	nil	nil	nil	50
13	Have you been asked to stay away from work or social groups?	16	12	nil	22	nil	nil	nil	50
14	Have you decided on your own to stay away from work or social group?	16	23	nil	11	nil	nil	nil	50
15	Because of your COVID-19, do people think you also have other health problems?	10	nil	nil	40	nil	nil	nil	50

Table 3: Type of stigma (n=100)

Stigma	COVID-test positive patients N=50	
	Mean(S.D)	Range
Enacted stigma	8.1(1.6)	2-8
Disclosure concerns	3.1(1.6)	0-6
Internalised stigma	3.7(2.5)	0-7
Externalised stigma	14.7(3.7)	1-20
Total stigma	30.5(6.5)	5-40

Table 4: Participant characteristics for COVID test positive patients

		Enacted stigma	Disclosure concerns	Internalized stigma	Externalized stigma	Total stigma
Age (years)	20-30	6.8(2.1)	2.5(1.4)	4.1(2.1)	14.5(5.3)	28.7(7.9)
	30-40	8.7(1.5)	3.2(1.3)	2.7(1.5)	15.9(3.8)	30.11(5.0)
	40-50	7.9(2.1)	2.6(1.7)	3.6(2.2)	14.7(3.5)	27.9(7.2)
	Above 50	8.5(2.6)	2.3(1.6)	3.7(2.3)	14.8(3.7)	28.3(7.6)
	p-value	0.077	0.257	0.058	0.288	0.578
Gender	Male	8.1(1.7)	3.4(1.7)	3.1(2.2)	15.6(4.6)	29.9(6.0)
	Female	7.1(2.2)	2.8(1.5)	3.5(2.3)	14.2(4.3)	27.6(7.2)
	p-value	0.032	0.47	0.48	0.111	0.15
Education	Illiterate	6.8(1.9)	2.9(1.4)	4.5(1.8)	14.3(3.6)	28.5(8.5)
	Primary	7.3(2.4)	2.9(1.6)	4.1(2.0)	14.3(5.5)	28.2(9.0)
	Secondary	7.4(2.2)	2.1(1.2)	3.6(2.1)	15.2(3.7)	26.6(6.7)
	Tertiary	8.9(0.7)	3.3(1.2)	2.0(1.9)	16.7(1.5)	31.1(3.0)
	p-value	0.003	0.578	0.022	0.156	0.581
Occupation	employed	5.7(1.6)	1.7(1.2)	1.7(2.6)	7.7(7.5)	17.2(14.2)
	Unemployed	6.5(1.5)	2.5(1.6)	3.7(1.7)	13.7(3.7)	25.2(5.6)
	p-value	<0.001	0.001	0.068	0.005	0.007
Marital Status	Married	7.5(2.5)	2.6(1.8)	3.5(2.6)	13.5(5.3)	27.1(8.7)
	Unmarried	7.9(1.7)	3.1(1.1)	3.5(2.4)	15.7(3.8)	30.11(6.0)
	p-value	0.087	0.178	0.649	0.112	0.129
Residence	Rural	7.7(1.8)	3.2(1.2)	3.6(2.3)	15.1(5.9)	28.9(8.7)
	Urban	7.4(1.9)	2.9(1.2)	3.1(2.0)	15.4(3.4)	27.5(4.9)
	p-value	0.5988	0.369	0.058	0.812	0.741

Discussion

The development of COVID-19 virus, which is rapidly invading new regions all over the world, is threatening the existence of human civilization [15]. During pandemics, there is a widespread increase in stigma, as witnessed in the severe acute respiratory syndrome (SARS) epidemic or the bubonic plague [16-18]. The amount of shame and embarrassment associated with an infectious disease is completely determined by knowledge of the condition and accessible treatment choices [19]. The fear of COVID-19 is likely due to the disease's uncertain nature and unpredictable course, the perceived risk of acquiring the infection and the lack of FDA-approved treatment, the infection's unpredictable outcome, high fatality, and novelty, all of which can generate negative psychological responses such as maladaptive behaviour and avoidance among people. As a result, people are more likely to be labelled, stereotyped, and discriminated against, as well as treated differently, as a result of real or perceived links with the disease; thus, the first quantitative assessment study was conducted to determine the prevalence of stigma, its socio-demographic correlates, and association with time since discharge among COVID-19 survivors in a developing country. The major finding of our study is that survivors reported significant levels of enacted and perceived externalised stigma. Our findings are consistent with numerous accounts of discrimination, prejudice, and social isolation that occurred during previous pandemics [20, 21]. Our findings are consistent with those of a Hong Kong comparative research that found significant levels of externalised stigma among SARS survivors compared to

HIV/AIDS and TB [22]. For starters, stigma causes disgraces that put a person apart from others [23] and significantly worsens the pain of those suffering from the condition. Second, people with the disease may conceal symptoms to avoid discrimination and even important travel history, or those at risk of contracting it may delay seeking health care until it is too late, making community transmission easier and public health authorities' ability to control the pandemic more difficult. As a result, such an atmosphere can foster negative preconceptions and erode social cohesiveness. Third, stigma can motivate people to engage in physical violence and hate crimes [24, 25]. Stigma can also put pressure on the families of frontline healthcare professionals to abandon their professions and demotivate them from carrying out their normal tasks. We found little internalised stigma, implying survivor self-worth and confidence. Our findings contrast those of a research on HIV/AIDS patients in Hong Kong [26] and Uganda [27], in which such patients expressed feelings of worthlessness, remorse, humiliation, and self-blame. Our findings also contrast the findings of short-term and small-sample cross-sectional studies in Sierra Leone [28, 29], Liberia [30], Guinea [31], and the Democratic Republic of the Congo [32], which found that EVD survivors experience various kinds of internalised and enacted stigma. EVD survivors in Sierra Leone, on the other hand, faced considerable internalised stigma after returning to their communities, contrary to our findings. In contrast to our findings, Almutairi AF *et al.*, discovered that internalised stigma was frequent among frontline health care professionals in the Middle East Respiratory Syndrome (MERS) [33] COVID-19 survivors reported limiting social

interactions, losing connections, being unfriended on different social media sites, being verbally attacked, being called names, and receiving negative comments. These reports are consistent with the types of stigma described by other infectious illness survivors globally in the literature [34]. Our findings are also consistent with earlier studies of stigma among SARS victims in Hong Kong [35]. Stigma associated with SARS sufferers has been observed in many areas of daily life, including the workplace, schools, health facilities, restaurants, and shopping centres. The apparent relationship between SARS and ethnicity resulted in an unreasonable fear of Asians (particularly Chinese) in many areas of the world [36]. The stigma associated with SARS patients has been so severe that strong limitations on Asian tourists have been enforced [37, 38]. During the ongoing COVID-19 epidemic, several literary and media publications showed numerous cases of survivors facing performed stigma. In India, for example, a COVID-19 positive pregnant woman was abandoned by her family following her delivery. COVID-19 survivors also claimed being humiliated by their communities, being ordered to evacuate their homes by their landlords, being abandoned, being refused access to private transportation, being socially shunned, and being dismissed from their prior private employment [39].

COVID-19 survivors are shunned, preventing them from reintegrating into society. Loss of friends and social isolation can lead to increasing levels of psychological discomfort. Concerns about disclosure might result in delayed access to medical care, poor adherence to medical therapy, and a worse quality of life. Similar concerns have been raised during previous infectious pandemics [40, 41]. Other qualitative research on COVID-19 found similar outcomes, revealing that people suffered discrimination, mistrust, and avoidance by their neighbours, insecurity about their homes, workplace bias, and withdrawal from social activities, even after the epidemic was contained [42]. Individuals who lose their employment are unable to make ends meet, and this unexpected tragedy adds to their shame, frustration, sadness, and mental agony, eventually leading to functional impairment and increasing rates of suicide [43]. COVID-19 survivors frequently encountered externalised stigma in the form of others not wanting them near their children and people being uncomfortable with them. This might be explained by people's unjustified dread of COVID-19 survivors' contagiousness, even after they've recovered. Similar concerns were raised during past viral pandemics, which corroborate our findings [44]. Our data show that both enacted and internalised stigma are related to education. One of the probable explanations is that more education is connected with better career possibilities, a higher possibility of employment, and more public engagement, which increases the likelihood of experiencing enacted stigma. In our study, stigma dropped considerably with increasing time since discharge. Overholt *et al.* observed similar results, finding that stigma levels during follow-up visits were much lower than stigma levels at baseline visits [44]. As a result; it may be argued that the period immediately following community re-entry is the most stigmatised. Similar findings were found in the case of SARS, when stigma reduced but never entirely eliminated following the epidemic [36]. The mental health consequences of surviving COVID-19 are substantial, and prior research has found that psychological discomfort, anxiety, and

depression are common among COVID-19 survivors [45, 46]. Although the impact of COVID-19 stigma on survivors' mental health is unknown, stigma-related psychological distress and anxiety have been associated to poor mental health outcomes in HIV/AIDS patients [47]. Because infectious viral illnesses have comparable stigmatising characteristics, it is conceivable that the stigma associated with COVID-19 is leading to mental health issues among its survivors [48]. As a result, stigma reduction initiatives are expected to aid in reducing the mental health burden among COVID-19 survivors.

Conclusion

The current study showed that COVID-19 test positive survivors had higher levels of enacted and externalized stigma than negative peers. Males and those with a higher level of education were more likely to be stigmatized. As a result, methods to preventing and minimizing such stigma are required both during the epidemic and in its immediate aftermath.

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