



Covid-19 related stigma among survivors in Soroti District, Uganda, March 2020 to December 2021

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Summary

Introduction: Much remains unknown about COVID-associated stigma and psychosocial effects among survivors. We estimated the proportion of COVID-19 survivors in Soroti District who experienced stigma, assessed factors with stigma, and described the psychosocial effects of COVID-19-related stigma among survivors.

Methods: A case was any survivor with confirmed COVID-19 infection in Soroti District from March 2020-December 2021. We reviewed records from Soroti Regional Referral Hospital to identify hospitalized and outpatient cases. We interviewed all consenting case-patients in their homes using three tools. We used a semi-structured questionnaire to assess demographics, clinical condition, case management, and family support during illness. We used a validated psychometric tool to assess feelings of enticed, internalized or perceived stigma while ill [score range of 15-20 (no stigma), 21-25 (mild/moderate stigma), and 26-30 (severe stigma)]. We used the Depression, Anxiety, and Stress (DASS-21) tool to assess depression, anxiety, and stress while ill. Logistic regression was used to identify factors associated with experiencing stigma among the participants.

Results: Among 314 cases, 166 (53%) were female. Among 301 (96%) cases who responded to stigma questions, 112 (37%) felt severe stigma, 84 (28%) mild/moderate stigma, and 105 (35%) no stigma. Among cases reporting stigma, 176 (90%) received emotional and/or financial support from household members. Factors associated with stigma included having cough during their COVID-19 episode (PR=1.05, 95%CI: 0.99-1.45) versus no cough and being in home-based care (PR = 1.27, 95%CI: 1.02-1.56) versus being hospitalized. Among 303 participants reporting psychosocial effects, 264 (87%) experienced extremely severe depression, 64 (21%) extremely severe anxiety, and 167 (55%) extremely severe stress.

Conclusion: COVID-19 patients in Soroti District experienced stigma and associated psychosocial effects during their COVID-19 illness. Patient counselling and community sensitization by a psychosocial team might be considered to reduce the burden of psychosocial effects in future outbreaks.



Background

New diseases often confer stigma on affected persons [1]. Such treatment can negatively affect those with the disease as well as their caregivers, family, friends, and communities [2-4].

According to World Health Organization (WHO) and United Nations Children's Fund (UNICEF), the COVID-19 pandemic has incited stigma and discrimination amongst people who have or might have COVID-19[5]. A cross-sectional study conducted in China comparing COVID-19 survivors and those without COVID-19 showed stigma among the COVID-19 survivors in form of rejection, financial insecurity, internalized shame, and social isolation[6]. Further still, the study found out that being a COVID-19 survivor, having family members infected with COVID-19, being married, economic loss during the COVID-19 pandemic, and depressive symptoms were positively associated with higher stigma level[6].

A cross-sectional study conducted among the general population of Colombia indicated an association between high fear of COVID-19 and stigma (63.6%) [7]. Another study conducted in Kenya revealed that COVID-19 related stigma was common in Western Kenya, the teachers reported to have experienced (74%) and witness (48%) discrimination related to COVID-19 at their neighborhood [8].

In Uganda, stigma associated with COVID-19 has been a challenge. COVID-19 patients and survivors have been rejected in some communities, prevented from socializing with others and called derogatory names[2, 3, 9]. This is largely due to low levels of knowledge and misconceptions about COVID-19 among the population [10].

Understanding the burden and types of stigma associated with COVID-19 is important in designing interventions to address it. Stigmatization related to fear from COVID-19 may lead people to deny or ignore early symptoms that are clinically relevant for early stage management [3, 4, 11]. Reducing fear and stigma among individuals is vital to control the spread of COVID-19. We estimated the proportion of COVID-19 survivors who experienced stigma, assessed the factors associated with being stigmatized, and the psychosocial effects of COVID-19-related stigma among survivors and their families to inform control measures.



Methods

Study design

We conducted a cross sectional study to assess COVID-19 related stigma among COVID-19 survivors and their families in Soroti, Uganda. The study involved review of patients records from Soroti RRH COVID-19 treatment unit and other COVID-19 treatment units within Soroti District to generate a line list of survivors. They were then traced to their homes where interviews were conducted.

Study area

Soroti District was purposively selected since it had continued to register high numbers of cases at the time of this study. Soroti is located in Eastern Uganda approximately 325.2Km from Kampala Capital City. It has a population of 363,600 people and the major economic activity is agriculture[12]. The community in Soroti District is well known for drinking a local brew called “malwa” which is taken in a social gathering while sharing one pot and tubes.

Sample Size

At the time of this study, there was limited data on COVID-19-related stigma, we therefore used 50% as the prevalence of COVID19 –related to calculate the sample size, resulting in a sample size of 384.

Study variables and data collection

We collected data on demographics, COVID 19 related illness, and factors likely associated with COVID- 19 related stigma using an interviewer administered questionnaire. We also collected data on psychological effects using a standard psychometric tool.

Interviews were conducted using a semi-structured questionnaire along with a validated psychometric tool [12], the Depression, Anxiety and Stress (DASS-21) scale [13]. The following steps were considered while using the DASS-21 tool.



Depression, Anxiety, and Stress Scale - 21 Items (DASS-21)

The DASS-21- scale has been used in different studies to assess psychological effects of stigma, for example, in assessment of social stigma related to COVID-19 disease conducted in primary and secondary schools in Kenya[14].

The Depression, Anxiety and Stress Scale - 21 Items (DASS-21) is a set of three self-report scales designed to measure the emotional states of depression, anxiety and stress. Each of the three DASS-21 scales contains 7 items, divided into subscales with similar content. The depression scale assesses dysphoria, hopelessness, devaluation of life, self-deprecation, lack of interest/involvement, anhedonia and inertia. The anxiety scale assesses autonomic arousal, skeletal muscle effects, situational anxiety, and subjective experience of anxious affect. The stress scale is sensitive to levels of chronic nonspecific arousal. It assesses difficulty relaxing, nervous arousal, and being easily upset/agitated, irritable /over-reactive and impatient. Scores for depression, anxiety and stress are calculated by summing the scores for the relevant items and multiplying it by 2. The DASS-21 is based on a dimensional rather than a categorical conception of psychological disorder. Recommended cut-off scores for conventional severity is as detailed in Table 1.

Table 1: Categorization of psychosocial effects according to DASS-21

Classification	Depression	Anxiety	Stress
Normal	0-9	0-6	0-10
Mild	10-12	7-9	11-18
Moderate	13-20	10-14	19-26
Severe	21-27	15-19	27-34
Extremely severe	28-42	20-42	35-42



Data management and analysis

The data were then extracted from the Kobo collect tool into an excel sheet where the metrics and scores of symptoms and their severity were created and analyzed using Epi Info 7.2.2.6 and Stata 14.

We performed descriptive analysis of demographic characteristics and psychological effects of COVID-19 related stigma experienced by the participants. Results were presented in frequency tables as proportions and percentages, means, standard deviations and graphs. Participants with missing information on some of the stigma and DASS scale items were excluded from the overall scores' generation. Multivariate analysis to determine the factors associated with experiencing stigma was done using a Modified Poisson regression model at 0.05 level of significance.

Ethical consideration

The Ministry of Health of Uganda gave the directive and approval to carry out this investigation. In agreement with the International Guidelines for Ethical Review of Epidemiological Studies by the Council for International Organizations of Medical Sciences (1991) and the Office of the Associate Director for Science, CDC/Uganda, it was determined that this activity was not human subject research and that its primary intent was public health practice or disease control activity (specifically, epidemic or endemic disease control activity). This activity was reviewed by the CDC and was conducted consistent with applicable federal law and CDC policy. All experimental protocols were approved by the US CDC human subjects review board and the Uganda Ministry of Health and were performed in accordance with the Declaration of Helsinki. Covid 19 survivors verbal informed consent was obtained before the start of each interviews. We

Results

Demographics characteristics of study participants

Among 314 study participants, 166 (53%) were females. Most (64%) of the participants were married, 91(29%) were single, and (3)1% were cohabiting. Of the 314 participants,11637% had completed tertiary or University level, 106 (34%) reported to have attend secondary school, 72 (23%) attended to primary school and 12 (4%) had never attend to formal education.



COVID-19 illness related factors among the study participants

Of the 314 study participants, 192 (63.7%) could remember when they were diagnosed and 146(76%) of them were diagnosed in 2021. Most patients 223(75.5%) had experienced fever when they had COVID-19, 46.2% needed to go to the hospital and 60% of them were admitted for 7 to 14 days. Most patients 267 (85%) had been through home-based care, 77 (24.5%) participants had comorbidities and most of them 13 (16.9%) had hypertension. Among 304 participants who reported that their household members knew about their COVID-19 diagnosis, 274 (90.4%) of them reported that they were supportive of them (Table 2).

Table 2: COVID-19 illness related characteristics among the study participants

Characteristic (n=314)	Frequency (Percentage)
Year of admission (n=192)	
2020	28(14.6)
2021	146(76)
2022	18(9.4)
Symptoms you experienced during COVID-19?	
Fever	237(75.5)
Headache	199(63.4)
Cough	202(64.3)
Loss of taste	134(42.7)
Loss of smell	121(38.5)
General body weakness	208(66.2)
Flue or running nose	165(52.6)
Number of days in admission (n=145)	
	Range (1 day – 2 months)
0 – 6 days	25(17.2)
7 – 14 days	87(60)
15 – 21 days	15(10.3)
22 – 28 days	8(5.5)
> 28 days	10(6.9)



Was under home-based care at any point

Yes	267(85)
No	47(15)

Had a co-morbidities (n=77)

High blood pressure/hypertension	45(58.4)
Diabetes	13(16.9)
Asthma	8(10.4)
Sickle Cell	0(0)
Cancer	3(3.4)
Hepatitis B	2(2.6)
HIV/AIDS	8(10.4)
TB	1(1.3)
Mental illness	1(1.3)

Household members knew about COVID19 diagnosis

No	10(3.2)
Yes	304(96.8)

Reaction of the household members

All were supportive of me	274(90.4)
Some were supportive, but others were not	26(8.6)
None were supportive	3(1)

Kind of support rendered by household members

Provided food and fruits	176(56.1)
Provided medicines	164(52.2)
Prayers and counselling	86(27.4)

Unsupportive actions by household members

They kept distance and feared to come near me	17(5.4)
Some household members left	7(2.2)
Refused to wash my clothes	2(0.6)
Laughed at me	2(0.6)

Treatment by household members after recovery

All were supportive of me	264(88.4)
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Some were supportive, but others were not	29(9.6)
None were supportive	6(2)
Supportive actions after recovery	
Provided food and fruits	109(34.7)
Provided medicines	53(16.9)
Prayers and counselling	59(18.8)
Encouraged mask and sanitiser use	35(11.1)
Unsupportive actions after recovery	
Some people kept distance and feared to interact	15(4.8)
Other people besides household members who got to know about participant's illness with COVID 19	
Neighbours	250(79.9)
Extended family	182(58.2)
Co-workers	107(34.2)
Others specify	32(10.2)
Others	
No one else knew	34(10.9)
Church members	3(0.9)
Friends	17(5.4)
School mates	6(1.9)
Reaction of neighbours or extended family or co-workers	
All were supportive of me	129(41.2)
Some were supportive, but others were not	106(33.9)
None were supportive	78(24.9)
Supportive actions from neighbours/extended family/co-workers take while you were ill	
Provided food and fruits	69(21.9)
Provided medicines	36(11.5)
Prayers and counselling	73(23.2)
Visited and made regular phone calls	35(11.1)
Money and financial support	42(13.4)



Unsupportive actions by neighbours/extended family/co-workers take while you were ill

Family members were discriminated in public spaces such as markets, children play areas, bore holes and shops	38(12.1)
Blamed me for infecting them	5(1.6)
Discriminated at workplace and eventually stopped working	2(0.6)
They laughed at us	4(1.3)

Reaction by neighbours or extended family or co-workers) react when you recovered from COVID-19

All were supportive of me	144(46)
Some were supportive, but others were not	96(30.7)
None were supportive	73(23.3)

Supportive actions from neighbours/extended family/co-workers after you recovered

Encouraged use of masks and sanitiser	11(3.5)
Visited me at home	25(7.9)
Prayers and encouragement	81(25.8)
Provided food and water	46(14.6)
Provided medicines and drugs	17(5.4)
Provided money and financial assistance	39(12.4)
Helped with my work tasks	12(3.8)
I was given more leave days	5(1.6)

Unsupportive actions by neighbours/extended family/co-workers take after you recovered

Did not socialise with me	55(17.5)
Avoided my children and family members	31(9.9)
Laughed at me	5(1.6)

Stigma towards COVID-19 infected people and their families during the time of illness

Most of the participants 221 (70.6%), reported that they had been hurt by how people reacted when they learned they had coronavirus disease. One hundred two (61.5%) reported that they



had stopped socializing with some people because of their reactions to them having COVID-19 and 200 (63.9%) had lost friends because they had COVID-19. Most (54%) of the participants were very careful who they tell that they had COVID-19 and 172 (55.1%) worried that people who knew they had COVID-19 will tell others. Most (59%) felt that they were not as good as others after having COVID-19. One hundred ninety-seven (62.9%) reported that having had COVID-19 infection made them feel they are bad persons and 186 (59.8%) felt guilty because they were COVID-19 positive (Table 3).

Table 3: Participants responses to questions on stigma towards COVID-19 infected people and their families during the time of illness

	Yes(N(%))	No (N(%))
Enacted Stigma		
I have been hurt by how people reacted when they learned I had coronavirus disease	221 (70.6)	92 (29.4)
I have stopped socializing with some people because of their reactions to my having COVID-19	120 (38.5)	192 (61.5)
I have lost friends because I had COVID-19	113 (36.1)	200 (63.9)
Disclosure Concerns		
I am very careful who I tell that I had COVID-19	143 (46.0)	168 (54.0)
I worry that people who know I have had COVID-19 will tell others	140 (44.9)	172 (55.1)
Internalized Stigma		
I feel that am not as good as others because I had COVID-19	128 (41.0)	184 (59.0)
Having had COVID-19 infection makes me feel that I am a bad person	116 (37.1)	197 (62.9)
I feel guilty because I was COVID-19 positive	125 (40.2)	186 (59.8)
Perceived External Stigma		
Most people think that a person who has had COVID-19 is disgusting	160 (51.1)	153 (48.9)
Most people are afraid of a person who has had COVID-19	173 (55.6)	138 (44.4)
Most people who have had COVID-19 are rejected when others	174 (55.6)	139 (44.4)



find out

People I know would be treat someone who has had COVID-19 as an outcast	151 (48.2)	162 (51.8)
People know would be uncomfortable around someone who has had COVID-19	164 (52.6)	148 (47.4)
People I know would reject someone who has had Covid19	140 (45.2)	170 (54.8)
People I know would not want someone who had COVID-19 around their children	177 (56.7)	135 (43.3)

Self-reported stigma scores for the study participants

The participants' responses on the stigma items were given score of 2 for "yes" and 1 for "no", giving a score range of 15 (min)to 30 (Max). Overall final scores were generated, and participants were categorised as follows (15 - 20) as having experienced no stigma, (21 - 25) as mild/moderate and (26 – 30) as severe stigma. Participants with missing information or no responses on some of the items were excluded. Among 301 participants with complete responses to the questions on stigma experiences, 112 (37%, CI:31.9-42.8) were categorised as having experienced severe stigma, 84 (27.9%, CI:23.1-33.3) had experienced mild/moderate stigma, while 105 (34.9%, CI: 29.7-40.5) were categorised as not having experienced stigma.

Factors associated with self-reported stigma among COVID-19 survivors

At multivariate analysis after controlling for covariates, we found that COVID-19 survivors who had cough (PR=1.05, 95% CI: 0.99 – 1.45) and those who were in home-based care at any point of their COVID-19 illness (PR = 1.27, 95% CI: 1.02 –1.56) were more likely to experience stigma (Table 5). All the other factors assessed (time of diagnosis, comorbidities, and length of admission) did not have a statistically significant association with experiencing stigma amongst COVID19 survivors.



Table 5: Factors associated with self-reported stigma among COVID-19 survivors

Characteristic (n=314)	Experienced moderate/no stigma n= 189 (%) ref	Experienced severe stigma n=112 (%)	Crude Prevalence Ratio (95% CI)	Adjusted Prevalence Ratio (95% CI)
Symptoms				
Fever				
No	40 (21.2)	35 (31.3)	1.00	
Yes	149 (78.8)	77 (78.7)	0.73 (0.49 – 1.09)	
Headache				
No	62 (32.8)	49 (43.8)	1.00	
Yes	127 (67.2)	63 (56.3)	0.75 (0.52 – 1.09)	
Cough				
No	67 (35.5)	41 (36.6)	1.00	
Yes	122 (64.5)	71 (63.4)	0.97 (0.66 – 1.42)	1.05 (0.99 – 1.45)
Loss of taste				
No	111 (58.7)	61 (54.5)	1.00	
Yes	78 (41.3)	51 (45.5)	1.11 (0.77 – 1.62)	
Loss of smell				
No	117 (61.9)	64 (57.1)	1.00	
Yes	72 (38.1)	48 (42.9)	1.13 (0.78 – 1.64)	
General body weakness				
No	68 (36.0)	35 (31.3)	1.00	
Yes	121 (64.0)	77 (68.8)	1.44 (0.77 – 1.71)	
Flue or running nose				
No	90 (47.6)	50 (44.6)	1.00	
Yes	99 (52.4)	62 (55.4)	1.08 (0.74 – 1.57)	
Were you in home-based care at any point for your COVID-19?				
Yes	166 (87.3)	88 (78.6)	1.47 (0.94 – 2.31)	1.27 (1.02 –1.56)
No	23 (12.2)	24 (21.4)	1.00	1.00



Psychosocial effects of COVID-19 related stigma

We found that 22 (7.1%) of the study participants reported that they felt that life was meaningless, almost always, while 154 (49.5%) never found it hard to wind down. Most of them 193 (61.9%) never experienced trembling, 210 (67.5%) were never intolerant of anything that kept them from getting on with what they were doing. One hundred ninety-six (62.8%) were never unable to become enthusiastic about anything and 189 (60.6%) were never worried about situations in which they might panic and make a fool of themselves (Table 6).

Table 6: Participants responses to questions on psychosocial effects of COVID-19 related stigma

Variable	Frequency (Percentage)			
	Never (0)	Sometimes (1)	Often (2)	Almost always (3)
I found it hard to wind down*	154 (49.5)	121 (38.9)	18 (5.8)	18 (5.8)
I was aware of dryness of my mouth I experienced breathing difficulty (for example, excessively rapid breathing, breathlessness in absence of physical exertion) *	158 (50.6)	124 (39.7)	18 (5.8)	12 (3.9)
I couldn't seem to experience any positive feeling at all*	162 (51.9)	97 (31.1)	39 (12.5)	14 (4.5)
I found it difficult to work up the initiative to do things *	169 (54.2)	102 (32.7)	25 (8.0)	16 (5.1)
I tended to over-react to situations	181 (58.0)	94 (30.1)	28 (9.0)	9 (2.9)
I experienced trembling (for example, in the hands)	193 (61.9)	84 (26.9)	21 (6.7)	14 (4.5)
I felt that I was using a lot of nervous energy	182 (58.2)	85 (27.2)	29 (9.3)	17 (5.4)
I was worried about situations in	189 (60.6)	90 (28.9)	19 (6.1)	14 (4.5)



which I might panic and make a fool of myself				
I felt that I had nothing to look forward to	181 (58.2)	89 (28.6)	29 (9.3)	12 (3.9)
I found it difficult to relax	145 (46.5)	118 (37.8)	35 (11.2)	14 (4.5)
I felt down-hearted and blue	169 (54.3)	103 (33.1)	29 (9.3)	10 (3.2)
I was intolerant of anything that kept me from getting on with what I was doing	210 (67.5)	74 (23.8)	19 (6.1)	8 (2.6)
I felt I was close to panic	144 (46.2)	111 (35.6)	40 (12.8)	17 (5.5)
I was unable to become enthusiastic about anything	196 (62.8)	91 (29.2)	16 (5.1)	9 (2.9)
I felt I wasn't worth much as a person	183 (58.8)	90 (28.9)	25 (8.0)	13 (4.2)
I felt that I was rather touchy	154 (49.8)	115 (37.2)	32 (10.4)	8 (2.6)
I was aware of the action of my heart in the absence of physical exertion (for example, sense of heart rate increase, heart missing a beat)	191 (61.2)	95 (30.5)	16 (5.1)	10 (3.2)
I felt scared without any good reason	151 (48.4)	104 (33.3)	40 (12.8)	17 (5.6)
I felt that life was meaningless	173 (55.6)	96 (30.9)	20 (6.4)	22 (7.1)

Experiences of self-reported depression, anxiety and stress among COVID-19 survivors

Among 303 participants, 23 (7.6%) had experienced extremely severe depression, 63 (20.8%) extremely severe anxiety and 14 (4.6%) extremely severe stress. Moderate depression experienced by 72 (23.8%), moderate anxiety by 42 (13.9%) and 45 (14.9%) experienced moderate stress. Mild depression 26 (8.6%), 18 (5.9%) mild anxiety and 75 (24.8%) experienced mild stress. A range of 42 – 52% were categorized as having not experienced any form of depression, anxiety, or stress.



Discussion

We assessed COVID-19 related stigma among COVID-19 survivors and their families and found a low prevalence of stigma. Most of the cases that reported stigma, also highlighted having received both emotional and financial support from their household members. Having cough and being in home-based care were associated with COVID-19-related stigma. Among the COVID-19 survivors who reported psychosocial effects, majority reported to have experienced extreme severe depression, about half experienced extreme stress, and only 21% had extremely anxiety.

Overall, this study found a lower level of prevalence of stigma among participants. However, most people reported having been hurt by how the community reacted towards them upon learning that they had corona virus. These findings are consistent with the study conducted in Uganda which reported rejection, fear and ostracism towards the affected, infected and survivors [15, 16]. Respondents revealed having undergone through enacted stigma as the highest number of them felt hurt by the reaction of the community towards their status, and this made some respondents to conceal their covid-19 positive status due to the perception that, the community was afraid of whoever would be got with the virus and would suffer from rejection. This study further observed that, although a greater percentage of respondents never worried about their positive status, they felt subjected to psychological effects such as; perception of meaningless life and inability to cope with the situation. The experience has been cited by a similar global survey which involved 173 countries, and reported nearly a third of participants believed that people who had COVID-19 were not respected by the community [17].

This study further revealed that people who cough and home-based care were more stigmatized compared to those who were hospitalized.

Conclusion

COVID-19 survivors in Soroti District, Uganda experienced relatively low levels of stigma compared to similar studies in other countries like Iran and Kenya. Having cough and being in home-based care were associated with stigma. The COVID-19 survivors experienced depression, fear, and anxiety during their COVID-19 illness.

We recommended patient counselling and community sensitization by psychosocial specialists to reduce the burden of psychosocial effects in future outbreaks.



Conflict of Interest

All authors declare that they have no competing interests.

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