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A crowdsourced intervention to decrease hepatitis B stigma in men who have sex with men in China: a cohort study

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Summary

Stigma against people with hepatitis B virus (HBV) is a barrier to prevention, diagnosis, and treatment of HBV in China. Our study examined an innovative intervention to reduce HBV stigma among men who have sex with men (MSM) in China. We extracted data from a randomized controlled trial conducted in May 2018, where the intervention consisted of crowdsourced images and videos to promote viral hepatitis testing and reduce HBV stigma. HBV stigma was assessed using a 20-item scale at baseline and four weeks post-enrollment. Participants were divided into three groups based on their exposure to intervention: full exposure, partial exposure, and no exposure. Linear regression was used to determine associations between baseline stigma and participant characteristics. Data from 470 MSM were analyzed. Mean participant age was 25 years old and 56% had less education than a college bachelor's degree. Full exposure to intervention was associated with significant stigma reduction (adjusted beta = −3.49; 95% CI = −6.11 to −0.87; p = 0.01), while partial exposure led to stigma reduction that was not statistically significant. The mean stigma score was 50.6 (SD ± 14.7) at baseline, and stigma was most prominent regarding physical contact with HBV carriers. Greater HBV stigma was associated with not having a recent doctor's visit (adjusted beta = 4.35, 95% CI = 0.19 to 8.52; p = 0.04). In conclusion, crowdsourcing can decrease HBV stigma among MSM in China, and may be useful in anti-stigma campaigns for vulnerable populations in low- and middle-income countries.

Conflict of Interest Statement: The authors declare no conflicts of interest.

Keywords

crowdsourced; China; hepatitis B virus; men who have sex with men; stigmatization

1 Introduction

China has the largest population of people living with hepatitis B virus (HBV) infection in the world.[1] Despite government policies to protect the rights of HBV carriers,[2,3] stigma against HBV remains common in China.[4–6] Individuals with HBV suffer from social isolation and denial of employment and educational opportunities.[7,8] Additionally, HBV stigma has led to coerced testing, agencies that provide falsified HBV test results, and suicide.[9–12] Finally, HBV stigma may cause delays in seeking health services, especially HBV vaccination[13,14] and HBV testing.[15–17] Decreasing stigma against HBV is thus an essential step toward the World Health Organization (WHO) Sustainable Development Goal of eliminating HBV by 2030.[18]

In the literature, stigma is often defined as a discrediting attribute that reduces an individual's status in society.[19] For our study, we operationalize HBV stigma as a social process involving discrimination at work or at school, devaluation in interpersonal relationships, fear of physical contact, or shame and blame towards persons with HBV. These four domains have been identified in the HBV stigma literature[17,20,21] as key attributes and create a framework for assessing HBV stigma.

Several gaps exist in the HBV stigma literature. First, measures of HBV stigma are inconsistent.[22] Second, studies frequently conflate evaluations of stigma with that of HBV knowledge,[22–28] despite evidence showing that knowledge does not necessarily correlate with stigma.[17,29,30] Third, there are few reports on interventions to reduce HBV stigma. Among publications in English, studies on HBV stigma have been observational and limited in scope, or do not assess stigma quantitatively.[22,31] To fill these gaps, rigorous research on interventions for HBV stigma is urgently needed.

Crowdsourcing may be an effective way to decrease HBV stigma. Crowdsourcing presents a problem to the public, collects contributions of potential solutions, and then shares solutions with the public.[32] As a strategy for community engagement, crowdsourcing directly engages target communities in intervention design. Community engagement has been shown to reduce health-related stigma.[33,34] One example of crowdsourcing is a challenge contest, where individuals are invited to submit solutions to a problem, and the winners receive recognition and a prize. Challenge contests in China have been shown to promote healthy behaviors such as condom use and HIV testing.[35,36] In 2017, a network of community-based organizations and the WHO organized a challenge contest in China that aimed to increase viral hepatitis testing and decrease hepatitis stigma.[37] Two images and two videos were selected from 168 entries and served as the intervention.

In this study, we evaluated the effectiveness of the crowdsourced intervention to decrease HBV stigma among MSM and also examined correlates of HBV stigma at baseline. We chose to evaluate HBV stigma in this population because MSM have a greater burden of

HBV infection compared to the general public in China[38] and are at increased risk of HBV transmission through high risk sexual activity.[39] The high rate of cell phone and social media use in China[40] allowed us to reach men nationwide to conduct a social media-based intervention.

2 Methods

2.1 Study Design

In this retrospective cohort study, we conducted a secondary analysis of a nationwide randomized controlled trial (RCT) (Clinical Trials #NCT03482388). Details of the trial methods and study design are described elsewhere.[37] In brief, the RCT aimed to study the effect of a crowdsourced intervention on promoting hepatitis B and C testing among MSM in China. The study was conducted throughout the month of May, 2018. Recruitment and informed consent were conducted via WeChat (Tencent, Shenzhen, China), a popular mobile messaging and social media application in China. The intervention was delivered via WeChat after enrollment. Baseline and follow-up surveys were conducted at enrollment and four weeks post-intervention, respectively.

2.2 Crowdsourced Intervention

The intervention consisted of materials that were developed through a crowdsourcing approach. In 2017, thirteen organizations in China including CBOs, universities, and government-based organizations collaboratively launched a nationwide public challenge contest. Individuals and teams were invited to submit original images or short videos to promote chronic viral hepatitis testing and combat hepatitis stigma. A total of 168 submissions were collected and judged by a panel of community representatives and hepatitis experts based on the following criteria: creativity, capacity to promote viral hepatitis testing, capacity to address HBV stigma, and potential to be shared widely on social media. Eight finalist entries were selected based on these criteria and received prizes as well as national recognition at the 2017 China Hepatitis Forum in Beijing. Finally, 60 MSM were asked to score the eight finalist entries, and the four top scoring entries (two images and two videos) were used for the final multimedia package as intervention.[37]

2.3 Participants

At the time of recruitment, participants were included if they were 16 years or older, born biologically male, currently resided in mainland China, and reported previous anal sex with a man. Participants were excluded if they reported ever testing for hepatitis B or C, or prior vaccination for hepatitis B. Our analysis consists of 470 Chinese MSM who completed both the baseline and follow-up surveys of the previously described RCT to promote hepatitis testing. Based on self-reported exposure to the intervention materials, the participants were divided into three groups: full exposure, partial exposure, and no exposure. Participants in the full exposure group viewed all four materials in our intervention package, while participants in the partial exposure group viewed one to three materials. Participants in the no exposure group viewed none of the materials.

2.4 Data

Responses to the relevant survey items were extracted from the RCT dataset and grouped into the following categories: (1) sociodemographic characteristics, (2) HBV stigma, and (3) healthcare seeking behaviors.

2.4.1 HBV stigma—Stigma was assessed using the 20-item Toronto Chinese HBV Stigma Scale. This scale was used as it had been previously used to assess the correlation between HBV stigma and healthcare behaviors, and had been validated in a Chinese-speaking population with a Cronbach's alpha of 0.90.[15] The items were organized into four domains: 1) Work/school Discrimination, 2) Interpersonal Relationships, 3) Physical Contact, and 4) Shame/Blame. Participants rated each item on a Likert-type scale from 1 to 5 (1=strongly disagree, 5=strongly agree). The score per item was summed for the total stigma score (range 20 to 100), with higher scores indicating greater HBV stigma. Finally, a mean score per question for each stigma domain was calculated (range 1 to 5). Individual items of the stigma scale are included in Supplement 1.

2.4.2 Healthcare seeking behavior—Participants were asked to report the time since their last doctor's visit. Having a recent doctor's visit was defined as seeing a doctor within the past two years.

2.3 Statistical Analysis

Data were analyzed using the SAS Software Version university-6p.2/6p.2.a70b47b86698-1-1 (Cary, North Carolina, USA). Descriptive analyses were conducted to characterize the study population and check for data distribution. Chi square and t-test were used to assess the sociodemographic differences among the exposure groups. The impact of intervention was evaluated based on the change in stigma score for each exposure group (follow-up stigma score minus baseline stigma score). Linear regression was used to evaluate the association between different degrees of intervention exposure and change in stigma. Potential confounders specified a priori (age, residence, education, and occupation) were included in the adjusted model.

Linear regression was used to evaluate the correlations with HBV stigma. To isolate the correlations between HBV stigma and residence and healthcare seeking behavior, the model was adjusted to control for sociodemographic factors (age and education) that may contribute to HBV stigma.

3 Results

3.1 Participant characteristics

The sociodemographic and behavioral characteristics of the 470 MSM in this study are shown in Table 1. The mean age was 25 years old. The majority lived in urban areas, were students, had never been married, and self-identified as gay. More than half (56%) of the participants had less than a college bachelor's degree, and the majority (81%) earned a median annual income of 8,780 USD or less (average annual income in 2017 in China was

7,712 USD[41,42]). In terms of healthcare seeking behaviors, 89% had a doctor's visit within the past two years.

The three exposure groups (no exposure, partial exposure, and full exposure) differ significantly only in sexual orientation and healthcare seeking behavior. Participants who identified as gay were less likely to report full exposure to intervention, compared to partial or no exposure (82%, vs. 93% and 87% respectively, $p = 0.02$). Additionally, participants who had a doctor's visit in the last two years were less likely to report full exposure to intervention, compared to partial or no exposure (72%, vs. 85% and 79% respectively, $p = 0.03$). Baseline stigma was not significantly different across the exposure groups. The remaining characteristics were also similar across groups.

3.2 Changes in HBV stigma after intervention exposure

Participants with full exposure to the intervention reported a decrease in HBV stigma score by 3.7 points from baseline. There was less decrease for participants with partial exposure and no exposure to intervention (decreased by 1.6 points and 0.4 points respectively). Full exposure to the intervention was associated with a statistically significant decrease in stigma compared to no exposure (adjusted beta = −3.49; 95% CI: −6.11 to −0.87; $p = 0.01$). The stigma score was also decreased when comparing full to partial exposure, as well as when comparing partial to no exposure, although these differences were not statistically significant. Stigma score outcomes of each exposure group are shown in Table 2. No baseline characteristics were found to modify the effect of intervention on stigma.

Additionally, full exposure to the intervention was associated with consistently greater reduction in stigma across all four stigma domains (Figure 1b). In three of the four domains, stigma reduction was statistically significant compared to no exposure (Supplement 2). The physical contact domain exhibited the greatest absolute and relative reductions, although these changes were not statistically significant across the exposure groups.

3.3 Correlates of HBV stigma

At baseline, the mean stigma score for the 470 participants was 50.7 (SD ± 14.6), and the scale was internally reliable (Cronbach $\alpha = 0.94$). Figure 2 shows the mean score per item in each stigma domain. Participants had the greatest stigma in the physical contact domain (mean score per question = 2.70, SE ± 0.04), where 52% (243/470) of participants believed that persons with HBV should not work with children, and 47% (202/470) felt they should not work in restaurants. Participants had the least stigma in the blame/shame domain (mean score per question = 2.02, SE ± 0.03) where 4% (18/470) of participants believe persons with HBV did something wrong to deserve their illness, and only 2% (10/470) believed HBV carriers should be ashamed. A summary of all baseline responses can be found in Supplement 1.

Not having seen a doctor within the past two years predicted greater HBV stigma (adjusted beta 4.35, 95% CI = 0.19 to 8.52; $p = 0.04$). Other characteristics were not found to predict HBV stigma (Table 3).

4 Discussion

HBV stigma is a major health issue in China. HBV stigma is a barrier to HBV testing and prevention, and people with HBV face discrimination in both healthcare and daily life. Our study is the first to characterize HBV stigma among MSM, who are at increased risk of HBV.[38] This is also the first study to quantitatively evaluate an HBV stigma intervention. We find that a crowdsourced intervention led to a decreased HBV stigma among a sample of MSM in China. Our study also breaks new ground by using crowdsourcing to develop a stigma reduction intervention. Finally, we note characteristics that predict greater HBV stigma, which can guide the targeting of future interventions.

4.1 Impact of crowdsourcing on stigma

Our study found that the crowdsourced intervention was associated with a modest but statistically significant reduction in HBV stigma. This reduction was consistently greater across all four domains of HBV stigma for participants fully exposed to the intervention, compared to participants with partial and no exposure. Furthermore, the intervention exhibited a dose-response effect on the stigma score. Our findings corroborate prior studies on community-based interventions and their significant impact on stigma towards mental health and HIV.[34,43,44] Crowdsourced interventions may be successful in effecting social attitudes such as stigma because they are created by the community for which it is intended. This ensures that the interventions are both relevant and engaging to the community, and thus more likely to be successful.[45,46] In fact, the importance of community engagement in destigmatizing HBV has been noted in practice.[47] Indeed, our intervention was associated with only a small decrease in stigma score. This is to be expected for our brief intervention, as stigma is a complex social process that takes time and reinforcement to change. Community-led campaigns against HIV stigma have, when implemented on the scale of months and years, demonstrated significant and sustained effects.[43,44] We found that exposure to a greater intervention dose trended towards greater stigma decrease, suggesting that stigma reduction may be more pronounced if the participants are exposed more consistently and over a longer intervention period, allowing for more frequent reinforcement of non-stigmatizing perceptions and attitudes.

4.2 Correlates of HBV stigma

In our study, we found that fear of physical contact with HBV carriers was the greatest contributor to overall stigma. This may be related to fears of contracting HBV through contact or through sharing food and eating utensils with HBV carriers. These misconceptions are well documented among Chinese-speakers in China[21] and the U.S.,[20,21] as well as other East and Southeast Asian populations.[15,17,20,21,23,24,26] On the other hand, shame and blame towards HBV carriers was relatively low, which is also similar to prior studies.[17,21] Our findings demonstrate that HBV stigma among MSM in China is similar to HBV stigma in the general population. Thus, our crowdsourced intervention may be similarly effective in other populations.

Additionally, we found that participants had greater baseline HBV stigma if they did not visit a doctor within the past two years. A similar association between HBV stigma and time

to last doctor's visit was reported among East Asians living in the US.[48] This may be related to poor health literacy, which has been associated with stigma against mental health conditions and healthcare delay.[49] However, fear of experiencing HBV-related stigma itself may also delay healthcare for persons at risk of HBV.[50] This effect is known as anticipated stigma, and has been shown to delay healthcare for populations at risk of HIV and TB.[30,51,52] Our social media-based intervention may have greater success in reaching and influencing these disengaged individuals, compared to facility-based or in-person interventions.

4.3 Limitations

There are several limitations to our study. First, this was a secondary analysis of an RCT for hepatitis testing uptake, where stigma was a secondary outcome. Stigma is a complex and multifaceted process, and our study was not designed to capture all facets of stigma. However, our stigma scale items and stigma domains were designed based on validated HBV stigma instruments, and our correlates are consistent with prior studies among Chinese-speaking populations. Second, we conducted our analysis based on intervention exposure status rather than according to RCT assignment in the original study. We chose this analysis due to the extensive intervention sharing between the randomized and control groups, leading to substantial contamination. We chose to analyze the data in this way because it was more appropriate for evaluating the effectiveness of men being exposed to different levels of hepatitis testing promotion messaging. Third, although our recruitment process was community-based, we may not have reached men who were disconnected from the MSM community. These men may have attitudes toward HBV different from that of our participants. Nonetheless, we captured participants across a spectrum of sociodemographic categories that we believe to be representative of online MSM in China. Fourth, the brief four-week intervention period with a single follow-up point did not allow us to observe the sustainability of our intervention effect. A longer follow-up period with consistent intervention dosage may reveal greater effectiveness of the intervention. Finally, this study cannot determine the clinical significance of the small stigma score decrease found in our study. To our knowledge, there have been no score cutoffs associated with clinical outcomes in the HBV stigma literature. However, the intervention was still associated with a significant decrease in score, and lower stigma scores are associated with better clinical outcomes. Our study can serve as a reference for future research to establish clinical correlates of these score changes.

In summary, our study shows that crowdsourcing may be a novel and effective way to reduce HBV stigma among Chinese MSM. Further research is necessary to investigate how crowdsourced solutions to reduce stigma affect clinical outcomes. The application of our findings need not be limited to MSM, as we found HBV stigma in MSM to be similar to other Asian populations. Moreover, crowdsourcing interventions may be applicable to other types of health-related stigma in other vulnerable populations. This includes people who inject drugs and people living with HIV, where crowdsourcing challenges have had promising effects.[53] Given that crowdsourced interventions draw on local resources and act locally, this strategy may be feasible for stigma interventions in other low- and middle-countries.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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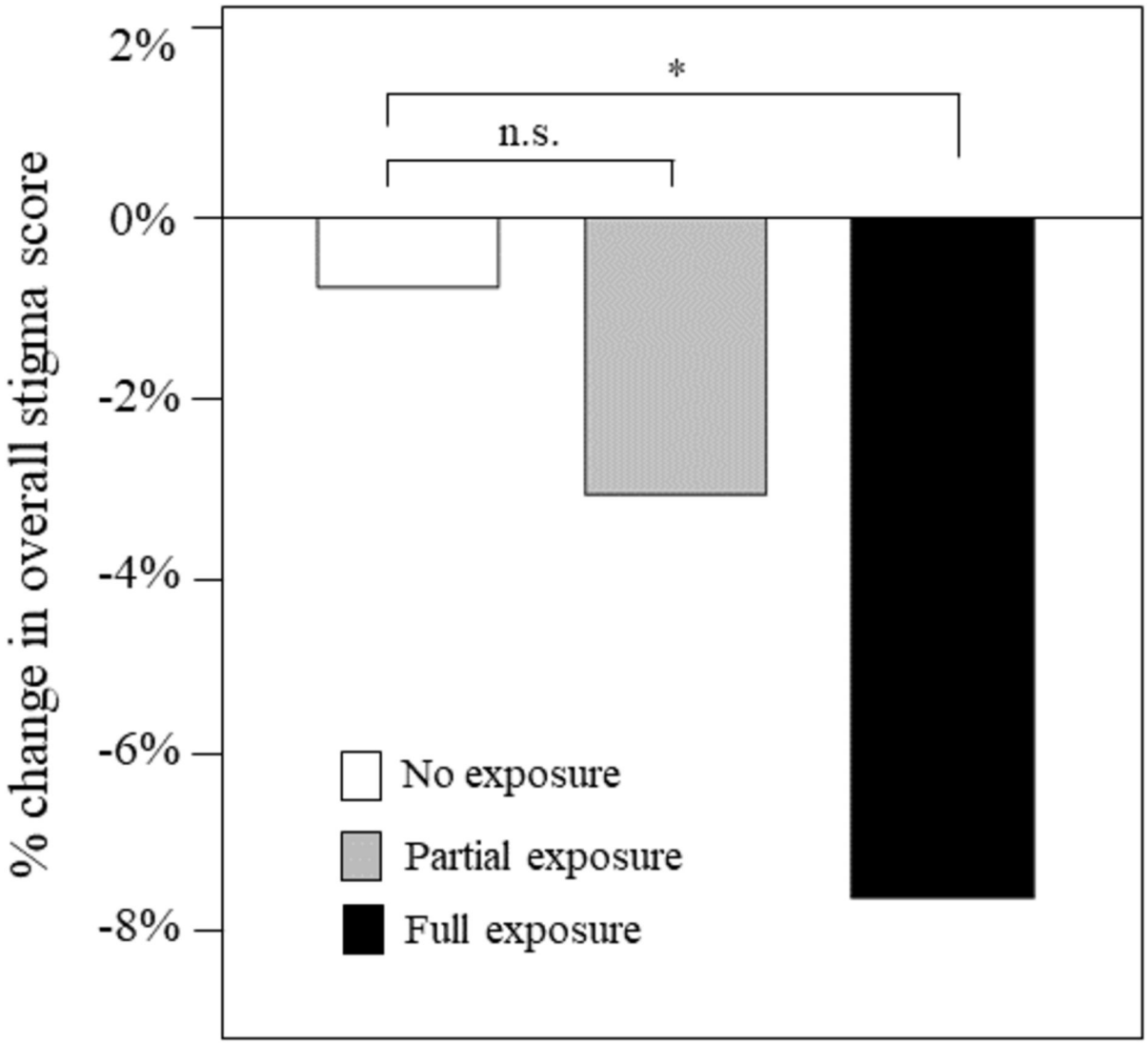

Figure 1a.
Comparison of percent change in total stigma score, by intervention exposure group.

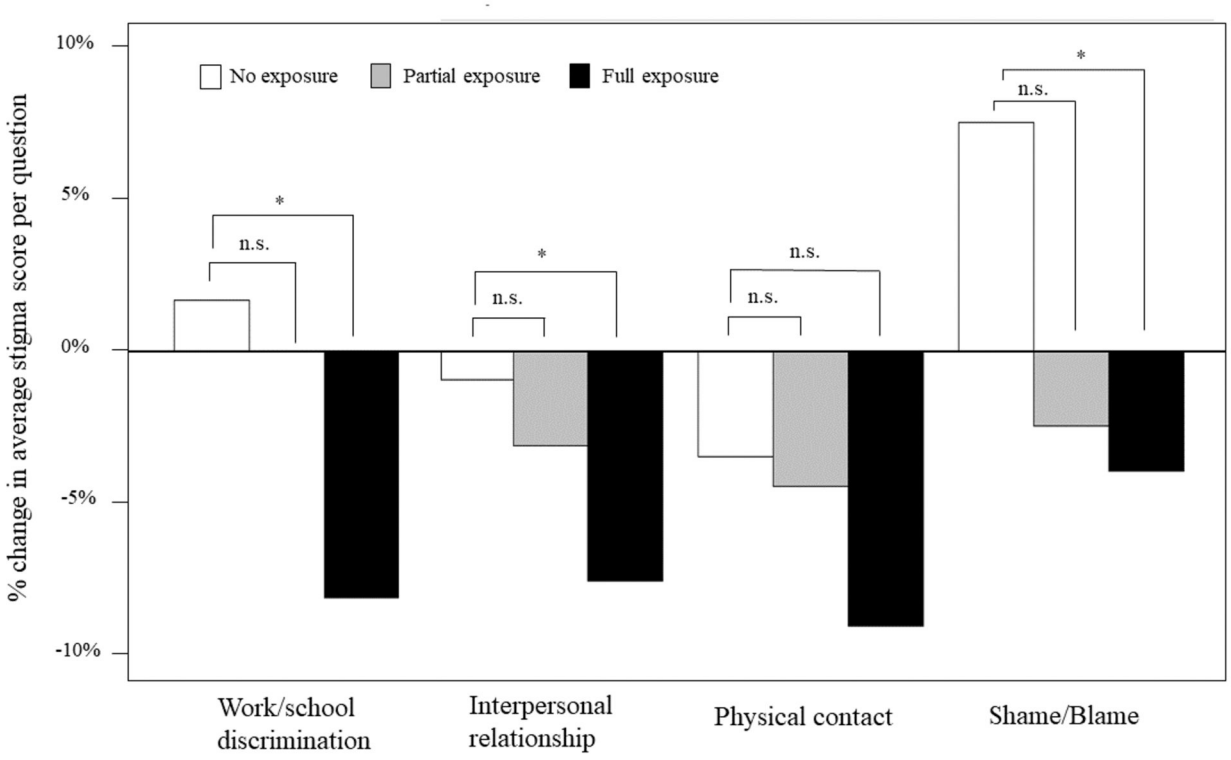

Figure 1b.

Comparison of percent changes in mean score per item in each stigma domain, by intervention exposure group.

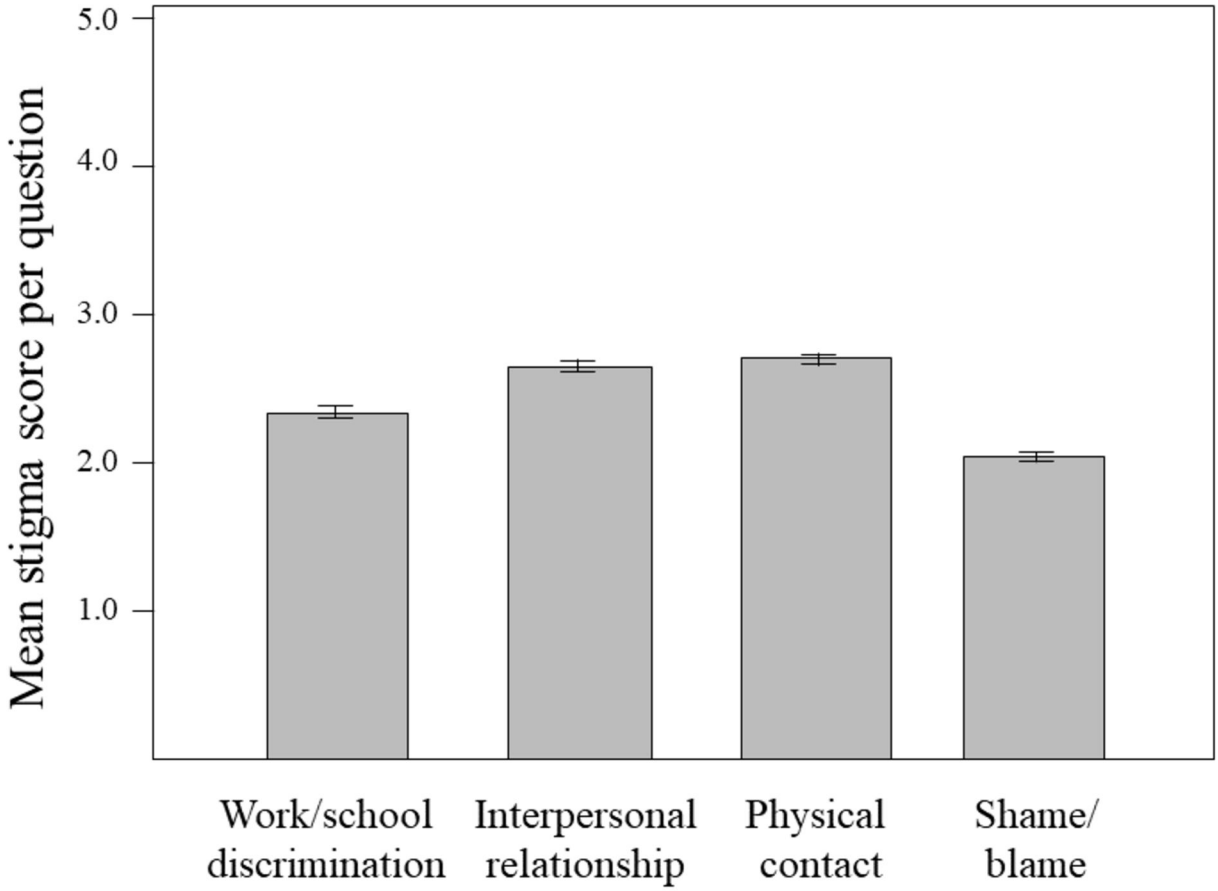

Figure 2.
Mean stigma scores and stardard errors per question of the four stigma domains for the 470 participants at baseline. A higher score indicates greater stigma.

Table 1.

Sociodemographic and behavior characteristics of the study subjects.

Characteristic[†]	Overall n = 470	Cohort based on intervention exposure			*p* value
		None n = 188	Partial n = 163	Full n = 119	
Age (*years*), mean ± SD	25.3 ± 6.7	26.1 ± 7.8	24.4 ± 6.3	25.5 ± 6.1	0.09
Current residence					0.49
Urban	388 (82.6)	157 (40.5)	137 (35.3)	94 (24.2)	
Rural	82 (17.5)	31 (37.8)	26 (31.7)	25 (30.5)	
Highest level of education					0.48
Below college[‡]	269 (57.2)	108 (57.5)	98 (60.1)	63 (52.9)	
College or above[‡]	201 (42.8)	80 (42.6)	65 (39.9)	56 (47.1)	
Occupation					0.39
Student	162 (34.5)	69 (36.7)	55 (33.7)	38 (31.9)	
Employed[§]	245 (52.1)	89 (47.3)	87 (53.4)	69 (58.0)	
Unemployed/other[¶]	63 (13.4)	30 (16.0)	21 (12.9)	12 (10.1)	
Annual income (USD)					0.93
≤ 8,780	385 (81.9)	155 (82.5)	132 (80.9)	98 (82.4)	
> 8,780	85 (18.1)	33 (17.6))	31 (19.0)	21 (17.7)	
Sexual orientation					0.02[*]
Gay	372 (79.2)	174 (92.6)	142 (87.1)	97 (81.5)	
Not gay	98 (20.9)	14 (7.5)	21 (12.9)	22 (18.5)	
Time to last doctor's visit					0.03[*]
Within the past 2 years	416 (88.5)	159 (84.6)	127 (77.9)	86 (72.3)	
More than 2 years ago	54 (11.5)	29 (15.4)	36 (22.1)	33 (27.7)	
Baseline stigma, mean ± SD	50.6 ± 14.7	51.1 ± 15.1	51.5 ± 14.2	48.6 ± 14.9	0.22
Follow-up stigma score, mean ± SD	49.0 ± 14.9	50.7 ± 14.4	49.9 ± 14.9	44.9 ± 15.2	<0.01[*]
Stigma change (follow-up minus baseline)	−1.7 ± 11.4	−0.4 ± 12.4	−1.6 ± 10.7	−3.7 ± 10.5	0.05[*]

[†] data are N (%) unless otherwise labeled

[‡] below college indicates vocational school, high school, or less; college or above indicates a bachelors, masters, PhD, or other higher degree

[§] includes farmers, civil servants, labor workers, office workers, and service/retail

[¶] includes unemployed, sex workers, and other uncategorized workers

[*] $p \leq 0.05$

Table 2

Comparison of change in stigma score between the different groups.

Exposure	Unadjusted beta[†]	95% CI	*p* value	Adjusted beta[†‡]	95% CI	*p* value
None	*reference*	-	-	*reference*	-	-
Partial	−1.20	(−3.59, 1.18)	0.32	−1.29	(−3.68, 1.10)	0.29
Full	−3.29	(−5.89, −0.68)	0.02[*]	−3.49	(−6.11, −0.87)	0.01[*]
Partial	*reference*	-	-	*reference*	-	-
Full	−2.08	(−4.77, 0.60)	0.13	−2.31	(−5.02, 0.40)	0.09

[†] beta indicates the difference in the change in total stigma score (scale 20 to 100).

[‡] adjusted for age, residence, education, and occupation

[*] ≤ 0.05

Table 3

Sociodemographic and behavioral variables associated with HBV stigma at baseline.

Variable	unadjusted beta (95% CI)	*p* value	adjusted beta (95% CI) ‡	*p* value
Age	0.15 (−0.05, 0.35)	0.14	-	-
Residence				
Urban	*reference*	-	*reference*	-
Rural	−2.99 (−6.50, 0.52)	0.09	−2.70 (−6.31, 0.91)	0.14
Highest level of education				
less than college †	−1.49 (−4.18, 1.21)	0.28	-	-
college or above †	*reference*	-	-	-
Time to last doctor's visit				
Within past 2 years	*reference*	-	*reference*	-
More than 2 years ago	4.24 (0.07, 8.40)	0.05 *	4.35 (0.19, 8.52)	0.04 *

† below college indicates vocational school, high school, or less; college or above indicates a bachelors, masters, PhD, or other higher degree

‡ adjusted for age and education level

* *p* value ≤ 0.05