

The background features a collage of medical and scientific imagery. At the top, hands are shown examining documents and a tablet. Overlaid are various icons: pills, a brain, a microscope, a clipboard, a heart rate monitor, a pill tray, and a first aid kit. A network of white lines and nodes is scattered across the scene, with some nodes highlighted in red. The overall color palette is dominated by soft reds, oranges, and whites.

HBV-TAG

2021 CONFERENCE

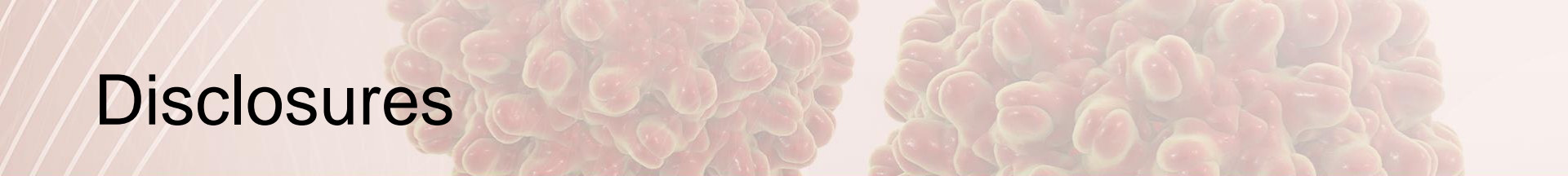
The background is a light orange color with various medical and scientific icons. On the left, a hand is shown holding a glowing heart. On the right, there is a cluster of hexagonal icons containing symbols for a clipboard, a heart rate monitor, a pill, a first aid kit, and a microscope. The overall theme is healthcare and medicine.

Stigma, Discrimination and Hepatitis B

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Disclosures



- None relevant
- See robertgish.com for all industry partnerships

Stigma and Discrimination Defined

- Stigma and discrimination among those with HBV infection is common worldwide, including in the US.
- HBV-related stigma can lead to social and emotional isolation, and HBV-related discrimination can limit employment and educational opportunities
- **Discrimination is defined as the unjust, unfair, or prejudicial treatment of a person on the grounds of their hepatitis B status.** In other words, being treated differently because of one's hepatitis B infection. For someone with hepatitis B, this can mean exclusion, denying benefits, denied employment, education, training, goods or services, or having significant burdens imposed on an individual due to their infection status.

Stigma defined

A decorative background image showing a close-up, microscopic view of biological cells, possibly bacteria or yeast, with a pinkish-red hue and a textured, bumpy surface. The cells are arranged in clusters and are slightly out of focus, creating a sense of depth.

- **Perceived stigma:** an individual's awareness of negative societal attitudes, fear of discrimination and feelings of shame.
- **Internalized stigma (self stigma):** an individual's acceptance of negative beliefs, views and feelings towards the stigmatized group they belong to and oneself.
- **Enacted stigma:** encompasses overt acts of discrimination, such as exclusion or acts of physical or emotional abuse; acts may be within or beyond the purview of the law and may be attributable to an individual's real or perceived identity or membership to a stigmatized group.
- **Layered or compounded stigma:** a person holding more than one stigmatized identity (e.g., HIV positive sero-status, sexual orientation, ethnicity).
- **Institutional or structural stigma:** stigmatisation of a group of people through the implementation of policy and procedures.

Adapted from:

Stangl A, Brady L, Fritz K. Measuring HIV stigma and discrimination: STRIVE Technical Brief. STRIVE, July 2012.

Loutfy MR, Logie CH, Zhang Y, Blitz SL, Margolese SL, Tharao WE, et al. Gender and ethnicity differences in HIV-related stigma experienced by people living with HIV in Ontario, Canada. PLoS ONE 2012;7(12):e48168.

Corrigan PW, Markowitz, FE, Watson AC. Structural levels of mental illness stigma and discrimination. Schizophrenia Bulletin 2004;30(3):481-491.

Complexity of Impact

Stigma and discrimination interplay with other physical, emotional and psychosocial factors that lead to reduced quality of life for people living with hepatitis B

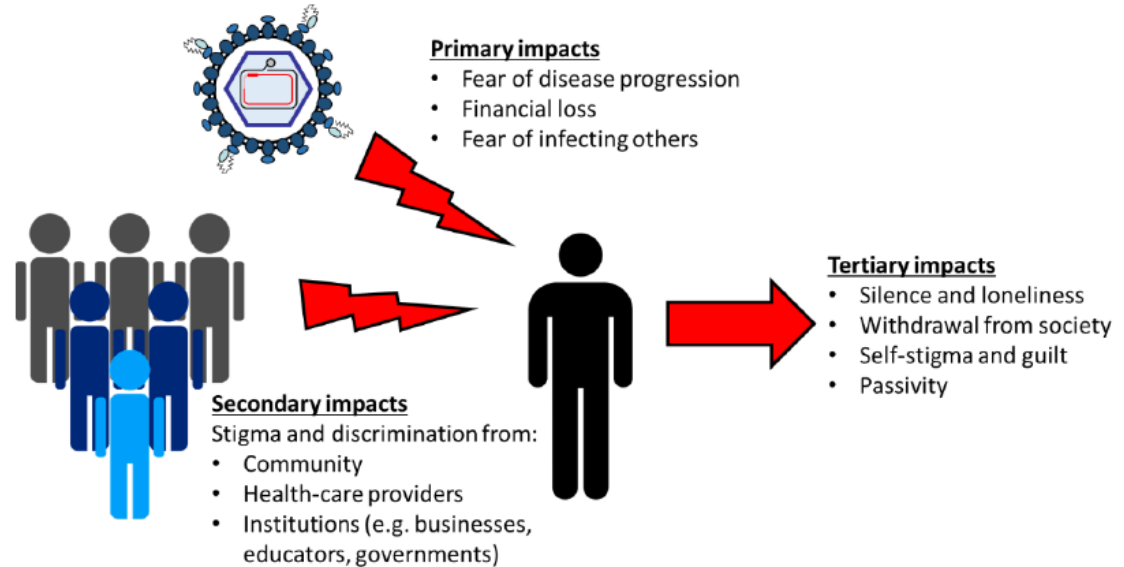


Figure 1. An overview of the psychosocial impacts of HBV infection on an individual living with CHB.

Stigma and Fear are Inter-connected

Driven by fear of being infected and promoted by the lack of accurate knowledge, leading to false perceptions about people with hepatitis B:

- MISCONCEPTION: HBV can be spread by sharing food or eating with someone
- MISCONCEPTION: HBV can be transmitted through simple physical contact
- MISCONCEPTION: HBV is only transmitted through promiscuous sex or illicit drug use
- MISCONCEPTION: HBV is caused by dirty conditions
- MISCONCEPTION: HBV is a genetic disease and means a family has weak genes
- MISCONCEPTION: HBV always leads to death

Discrimination is Widespread around HBV

- Reduced opportunities for education, employment, and residency/citizenship.
- Many countries do not provide legal protection against discrimination, and people with CHB can lose their jobs, be forced to leave school, or be denied childcare.
- Even if legal protections exist, poor enforcement of these laws mean stigma and discrimination continue.
- Many countries have immigration limitations, such that people with HBV cannot get visas or can be deported if they are diagnosed with HBV.
- In some countries, guest workers who are diagnosed with HBV are denied work/residence permits.
- This kind of government-sanctioned discrimination can be devastating and is another poorly-documented harm for people with CHB.

How does stigma impact people with HBV?

”

“Emotionally, I was subject to prejudice ... harassment from my coworkers, my roommates, I was rejected. I was telling them to get vaccinated. And I told them about the disease, but gradually they rejected me, and I feel alone.”

**-Gooksa from
Minnesota**

- Self-stigma and shame lead to decreased social interaction & isolation.
- People face harassment from community, family, employers and health care system.
- People avoid situations, such as education, job, dating, and marriage, to avoid disclosure of their HBV infection.

Impact of Stigma and Discrimination



- International survey of 1,707 people living with hepatitis B
- Many respondents lost jobs or professional opportunities due to discrimination
- Many reported being afraid to tell loved ones about their infection

Examples from Hepatitis B Foundation consultation line:

Stigma and discrimination associated with an HBV diagnosis led to significant barriers accessing employment opportunities.

- One individual described, “I am looking for online supports for her...She has a lot of concern about the stigma of the illness and worry that others will reject her if she discloses her status.”
- Another individual described that the stigma was preventing them from seeking medical care by sharing, “I have neither done further tests nor taken any medication. This is partly because of the cost of some of recommended tests and the stigma associated with it.”

Examples from Hepatitis B Foundation consultation line:

- **Individuals experienced loss of employment both within their country and when attempting to work abroad due their HBV diagnosis.**
- One individual reached out for help, sharing, “I was diagnosed with Hep B and I was stopped from going abroad to work. Medication for hepatitis B is not common in Uganda.”
- Permits are denied due to their HBV status, “...unfortunately I was hepatitis B positive and I was told my residence permit is denied.”
- Another individual shared fear of going to the hospital because of a diagnosis with HBV, “I read in the student handbook given to me that foreigners can be detained if discovered to have dangerous communicable diseases. I'm therefore scared of visiting any of the hospitals in (name removed) for a checkup.”
- This discrimination was even described in the United States Military, “I am Sargent First Class in the United States Army...I found out I had chronic Hepatitis B...Due to recent changes on the rules and regulations that [cover] my illness...the possibility that I will have to be medically separated with no compensation.”

Examples from Hepatitis B Foundation Interviews

- "At homes, we have cases where people in the home have hepatitis, they're giving their plates of food separate from others. And they have, they are giving beds bedding materials as different from others, they give me spoons different from others. There are some cases one I knew that had a separate room for them."
- "People know that the disease is transmitted immediately, and they act like you are sick. And you don't want anyone to know"
- "From my experience we are fighting two battles together. One battle is inside the body that we are facing every day as we take antiviral medicines that effect over mental health or physician health and in society we face discrimination, you know disrespectful manners, we face stigma about the disease."
- Misconceptions about transmission: "people think if you shake someone's hand, you will get hepatitis B."
- "They don't want people to know they are positive"

Examples from Hepatitis B Foundation Interviews

- Education based discrimination: "just last week we had a student who is a HBV infected person, I think she was studying as a nurse she was being forced to drop out and transfer to another curriculum."
- "A girl got a rejection in a medical college just because she was hepatitis B positive."
- Employment: Before you get employment, or maybe for scholarship we have to do screening, medical screening"
- In China or African countries for education they provide scholarship for African nations to send young people to universities to study in China now part of that practice is screening them for HIV, syphilis and all major infectious disease including hepatitis B and C. Those who are found to be positive, are essentially deported."
- "In shipping or going abroad, sometimes it's also a requirement [to get tested]."
- "Within Nigeria, we have people that are dropped from employment, especially some of the military organizations, they drop people."
- "I have seen people sacked from jobs and others who have lost their jobs."

HBV Stigma

Demographic Data

	Vietnamese in Chicago (<i>n</i> = 170)		Vietnamese in Ho Chi Minh City (<i>n</i> = 842)		<i>p</i> value
	Number of valid responses		Number of valid responses		
Age (mean ± SD years)	170	47 ± 16	842	36 ± 11	<0.001
Sex (% male/female)	169	46%/54%	842	40%/60%	0.191
Marital status (% married/single)	170	77%/23%	842	86%/14%	0.004
Education (% <high school/≥high school)	169	14%/86%	842	43%/57%	<0.001
Recalls testing for HBV (%)	165	44%	842	44%	0.966
Self-identified as HBV carrier (%)	166	9%	840	4%	0.005
HBV carrier in the family (%)	169	14%	840	14%	0.926
Vaccinated for HBV (%)	166	48%	842	33%	<0.001

HBV Stigma

Knowledge: Participants were asked to indicate whether the following statements about hepatitis B are true or false

Statement about hepatitis B	Vietnamese in Chicago <i>n</i> (%) correct	Vietnamese in Ho Chi Minh City <i>n</i> (%) correct	<i>p</i> value
Is preventable by vaccination	161/170 (95%)	811/842 (96%)	0.325
Can be treated with prescription medications	155/170 (91%)	753/842 (89%)	0.494
Can be spread by sexual intercourse	117/169 (69%)	383/842 (45%)	<0.001
Can be spread by blood	139/170 (82%)	639/842 (76%)	0.098
Can be spread during childbirth	122/170 (72%)	656/842 (78%)	0.083
Can be spread by eating raw shellfish	92/170 (54%)	578/841 (69%)	<0.001
Can be spread by sharing eating utensils	116/170 (68%)	379/842 (45%)	<0.001
Can cause lifelong infection	122/170 (72%)	441/842 (52%)	<0.001
Can cause advanced liver disease (cirrhosis)	150/170 (88%)	778/842 (92%)	0.073
Can cause liver cancer	145/170 (85%)	762/842 (91%)	0.042
Can be spread by someone who looks healthy	137/170 (81%)	632/842 (75%)	0.124
Carriers can only be identified by a blood test	159/170 (94%)	805/842 (96%)	0.245

HBV Stigma

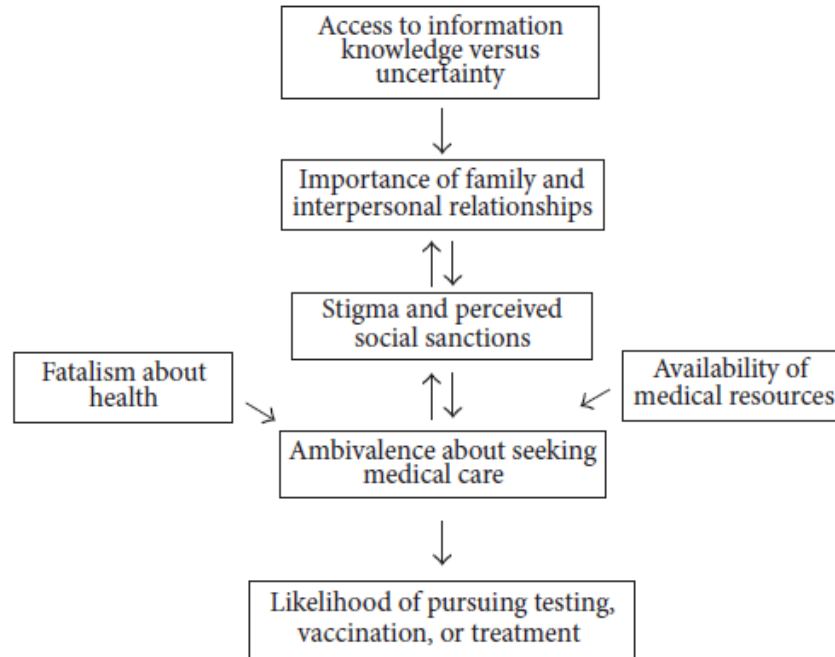
Responses to Stigma Items

Respondents were asked to provide their perceptions about people who are hepatitis B carriers.

	Number of valid responses	Vietnamese in Chicago				Number of valid responses	Vietnamese in Ho Chi Minh City				p value*
		Strongly agree	Agree	Disagree	Strongly disagree		Strongly agree	Agree	Disagree	Strongly disagree	
(i) Feel ashamed about having HBV	169	11%	18%	60%	11%	842	1%	16%	78%	5%	<0.001
(ii) Feel that they bring trouble to their family	170	14%	38%	42%	6%	842	1%	52%	45%	2%	0.839
(iii) Feel guilty about having HBV	170	9%	20%	61%	9%	842	1%	16%	78%	5%	<0.001
(iv) Put others at risk for HBV	170	13%	24%	54%	9%	842	2%	59%	37%	2%	<0.001
(v) Should avoid close contact with others such as kissing or hugging	170	16%	28%	46%	10%	842	2%	41%	54%	3%	0.897
(vi) Should not be isolated	170	22%	41%	30%	7%	842	8%	79%	11%	2%	<0.001
(vii) May be viewed by others as having a shameful sexually transmitted disease	168	8%	22%	61%	9%	842	1%	21%	73%	5%	0.011
(viii) Can be trusted not to bring harm to others	170	8%	43%	39%	10%	842	3%	60%	35%	2%	0.005
(ix) Can be trusted as friends	170	14%	58%	24%	4%	842	4%	83%	12%	1%	<0.001
(x) Are viewed as undesirable as a husband or wife	170	8%	17%	64%	11%	842	1%	27%	69%	3%	0.486
(xi) Might be discriminated against at school in the Vietnam	170	7%	22%	60%	11%	842	1%	19%	75%	5%	0.004
(xii) Might be discriminated against at work in the Vietnam	170	8%	21%	60%	11%	842	1%	20%	74%	5%	0.023
(xiii) Might be denied healthcare in Vietnam	169	6%	15%	66%	13%	842	1%	7%	82%	10%	<0.001

*For analysis pertaining to individual stigma items, responses were dichotomized as stigma (yes/no).

HBV Stigma



Multiple factors that have an impact on how HBV infection is perceived, which can affect psychological well-being and social interactions and serve as a barrier to seeking testing, vaccination, and treatment.

HBV Stigma

	Number of valid responses*	Strongly agree (%)	Agree (%)	Disagree (%)	Strongly disagree (%)	α	Stigma Score (mean \pm SD)†
Domain 1. Negative perception						0.81	1.95 \pm 0.57
Feel ashamed about having HBV	198	2	6	61	31		
Feel that they bring trouble to their family	200	5	31	46	18		
Feel guilty about having HBV	196	2	16	57	25		
Are viewed as undesirable as a husband or wife	199	3	9	58	30		
Domain 2. Social isolation						0.80	1.92 \pm 0.58
Should not be isolated	199	29	58	8	5		
Can be trusted not to bring harm to others	199	21	59	18	2		
Can be trusted as friends	199	24	68	7	1		
Domain 3. Fear of contagion						0.69	2.70 \pm 0.68
Put others at risk for HBV	198	10	60	24	6		
Should avoid close contact with others such as kissing or hugging	196	14	48	27	11		
Domain 4. Healthcare neglect						0.87	1.78 \pm 0.63
Might be denied healthcare in the US	196	1	7	55	37		
Might be denied healthcare in China	188	3	9	56	32		
Domain 5. Workplace/school stigma						0.93	2.08 \pm 0.67
Might be discriminated against at school in the US	197	1	19	58	22		
Might be discriminated against at work in the US	197	1	22	57	20		
Might be discriminated against at school in China	192	4	28	50	18		
Might be discriminated against at work in China	186	5	28	48	19		

Responses to stigma items and reliability estimates of the stigma domains. Respondents were asked to provide their perceptions about people with chronic HBV infection.

Cotler SJ, Cotler S, Xie H, Luc BJ, Layden T, Wong S
Journal of Viral Hepatitis, 2012, 19, 147-152

HBV Stigma

Hepatitis B Knowledge

Subjects were asked to indicate whether the following statements about HBV are true or false.

Statement: HBV...	Number of valid responses*	%Correct
Is preventable by vaccination	199	95
Can be treated with prescription medications	199	84
Can be spread by sexual intercourse	193	60
Can be spread by blood	196	90
Can be spread during childbirth	194	91
Can be spread by eating raw shellfish	196	31
Can be spread by sharing eating utensils	195	43
Can cause lifelong infection	188	75
Can cause advanced liver disease (cirrhosis)	198	98
Can cause liver cancer	198	92
Can be spread by someone who looks healthy	185	50
Carriers can only be identified by a blood test	192	94

HBV, hepatitis B virus. *Percentages are calculated based on the number of valid responses to each item.

HBV Treatment Study

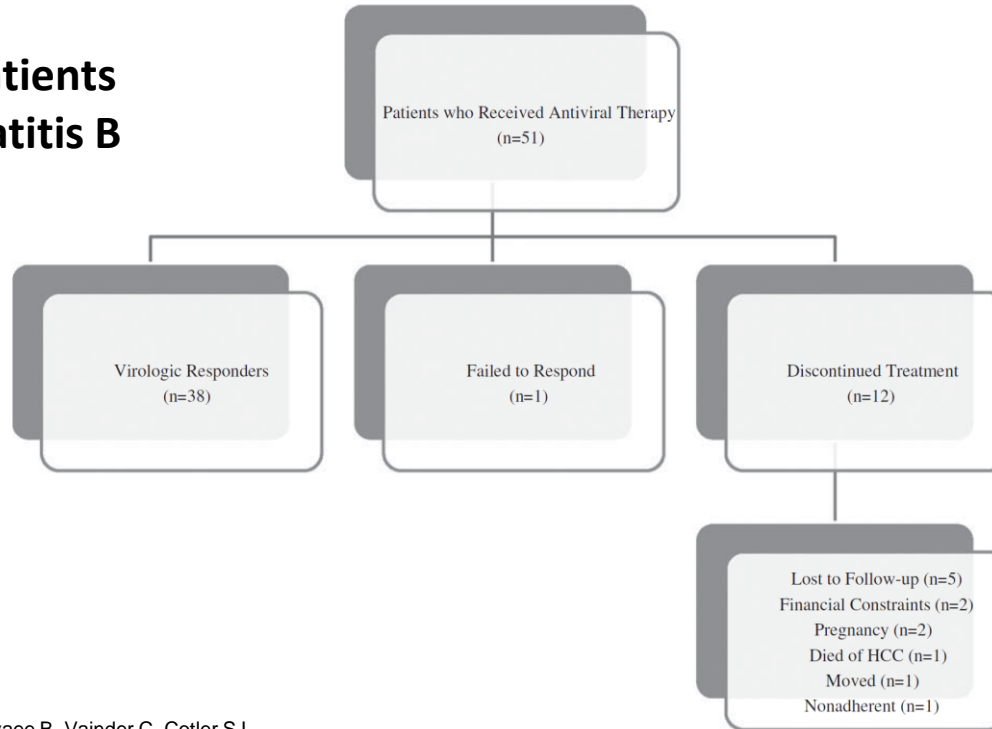
Demographic and Clinical Features of the Study Population

	All (n = 69)	Treated (n = 51)	Untreated (n = 18)	<i>P</i>
Age (y ± SD)	46 ± 14	46 ± 13	45 ± 16	0.66
Sex (male/female)	27/42	22/29	5/13	0.25
Chinese ethnicity (%)	100%	—	—	—
Insurance (yes/no)	61/8	48/3	13/5	0.02
HBeAg status (eAg + /eAg -)	36/33	30/21	6/12	0.19
Baseline DNA level (copies/mL) ± SD	225,480,532 ± 762,925,989	213,681,007 ± 770,732,328	258,912,521 ± 761,236,497	0.83
Mean follow-up (months ± SD)	34.9 ± 24.1	40.7 ± 23.3	18.7 ± 18.9	0.001

HBV indicates hepatitis B virus.

HBV Treatment Study

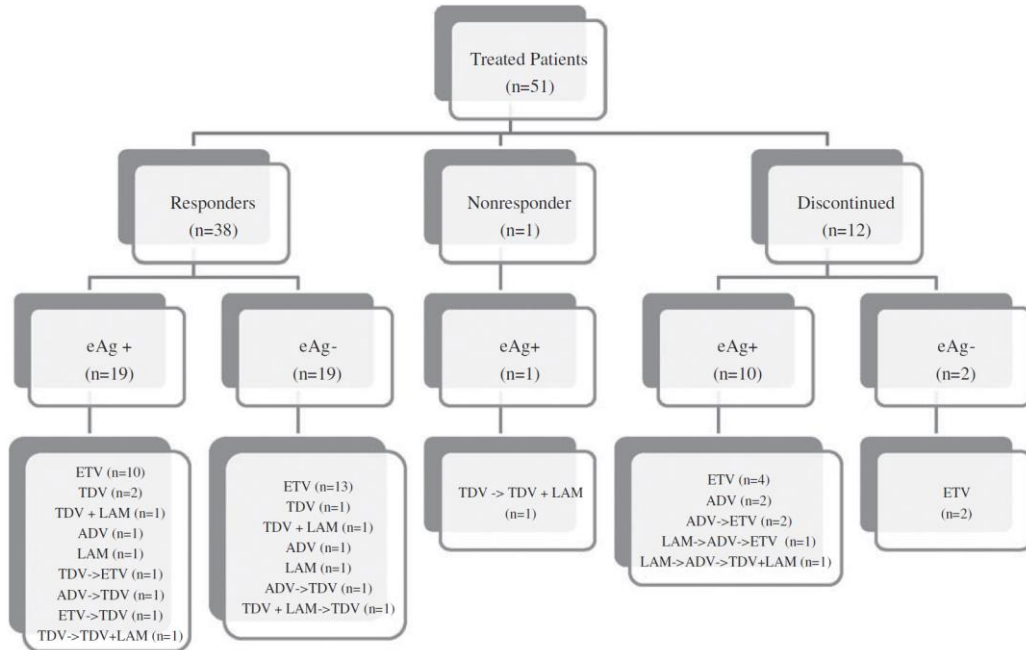
Outcomes of patients treated for hepatitis B



HBV Treatment Study

Medications used to treat hepatitis B by response/discontinuation and HBeAg status.

Arrows signify change in antiviral agent. ADV indicates adefovir; ETV, entecavir; LAM, lamivudine; TDV, tenofovir



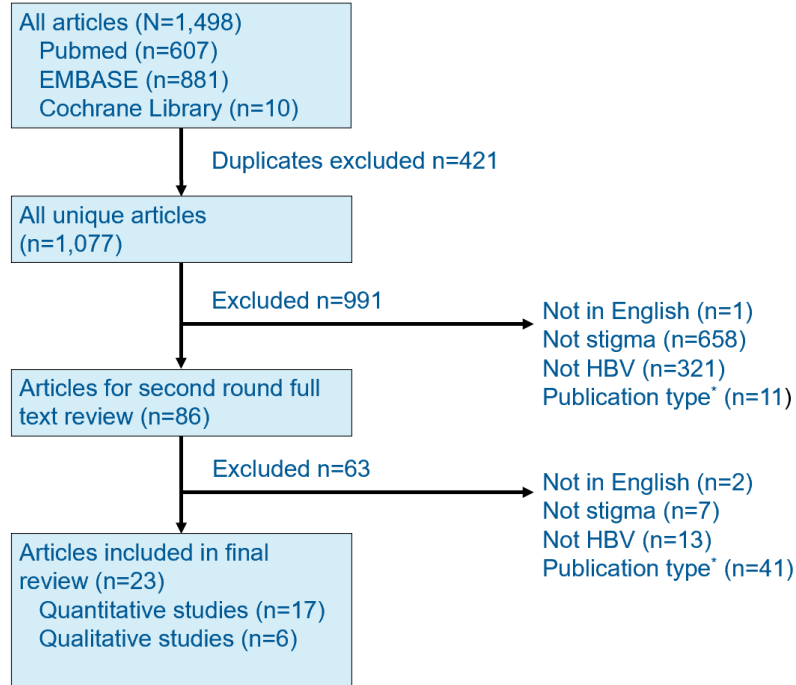
There was no measurement of stigma in this paper (Malespin)

- Action item
- Stigma measurement should be part of any study that looks at barriers, PROs, adherence and compliance measurements

The Nature & Impact of Stigma in Patients with Chronic Hep B: A Systematic Literature Review

- Stigma defined : *“typically a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgement about a person or group...and the judgement is in some way medically unwarranted.”*¹
- In many countries, people living with bloodborne diseases, such as hepatitis B virus (HBV), frequently experience disease-related stigma. For chronic diseases such as HBV stigma may be a life-long problem and can influence many areas of day-to-day life. This stigma often emanates from multiple origins, including preconceptions that the person may be an intravenous drug user (IDU) or is sexually promiscuous as well as an irrational fear of contagion, often fuelled by a lack of knowledge of transmission routes of HBV.

The Nature & Impact of Stigma in Patients with Chronic Hep B: A Systematic Literature Review



Methods

A systematic literature review was performed to identify qualitative and quantitative studies detailing HBV-related stigma.

Searches were performed using the PubMed, EMBASE and Cochrane Library databases.

*Publication type refers to articles that were excluded on the basis of being published in abstract form only, as well as case studies, commentaries, editorials, letters and narrative reviews

The Nature & Impact of Stigma in Patients with Chronic Hep B: A Systematic Literature Review

Study	Details
Carabez et al. 2014 (US) ²	Custom-built online questionnaire in Asian American ^a adults with chronic HBV infection
Cheng et al. 2017 (US) ³	Custom-built survey in Asian American ^a adults (HBV infected and uninfected)
Cotler et al. 2012 (US) ⁴	Development and validation of the HBV Stigma Instrument in Chinese immigrants to the US with chronic HBV
Dam et al. 2016 (US and Vietnam) ⁵	HBV Stigma Instrument (Cotler et al. ⁴) in Vietnamese adults in Vietnam and the US (HBV infected and uninfected)
Drazic et al. 2013 (Australia) ⁶	Modified version of the Social Impact Scale in adults with chronic HBV
Huang et al. 2016 (China) ⁷	Custom-built survey based on Cotler et al. ⁴ and Li et al. ⁹ in adults with chronic HBV and uninfected controls
Leng et al. 2016 (China) ⁸	Custom-built survey in rural Chinese adults who had moved to Beijing (HBV infected and uninfected)
Li et al. 2012 (Canada) ⁹	Toronto Chinese HBV Stigma Scale in Chinese ^a adults (HBV infected and uninfected)
Maxwell et al. 2012 (US) ¹⁰	Custom built survey based on Health Behavior Framework in four different Asian American groups (never tested for HBV)
Mohamed et al. 2012 (Malaysia) ¹¹	Custom built survey in chronic HBV patients
Poorkaveh et al. 2012 (Iran) ¹²	Stigma subscale of the HBQoL Questionnaire in chronic HBV patients
Spiegel et al. 2007 (US) ¹³	Development and validation of the HBQoL Questionnaire, including stigma subscale, in chronic HBV patients
Van der Veen et al. 2014 (Netherlands) ¹⁴	Custom-built survey in Turkish-Dutch immigrants (HBV infected and uninfected)
Wang et al. 2009 (Taiwan) ¹⁵	Custom-built survey in students (HBV infected and uninfected)
Yu et al. 2016 (China) ¹⁶	Custom-built survey in rural adults (HBV infected and uninfected)
Acosta-Gio et al. 2008 (Multinational) ¹⁷	Custom built survey in dental students in three Latin American countries
Li et al. 2007 (China) ¹⁸	Comparison of HCP attitudes towards HBV versus HIV patients based on case vignettes

^aSelf-identified
HBQoL: Hepatitis B Quality of Life Instrument; HCP, healthcare provider

Results

Seventeen quantitative studies were identified (Table 1), the majority of which were conducted in Asia or in Asian immigrant communities in North America. Six additional studies examined HBV-related stigma qualitatively, primarily through in-depth patient interviews. The majority of quantitative studies used different custom-built surveys to assess stigma, often based on previously published surveys in HIV, but three studies used the HBV Stigma Instrument designed by Cotler et al. (2012), which was specifically designed to evaluate stigma in HBV.

Stigma was consistently reported among HBV patients, who often felt embarrassed or ashamed due to being infected with HBV, and many believed that HBV patients should avoid close contact with others. Several studies also reported that being chronically infected with HBV would make a person less desirable as a spouse.

The Nature & Impact of Stigma in Patients with Chronic Hep B: A Systematic Literature Review

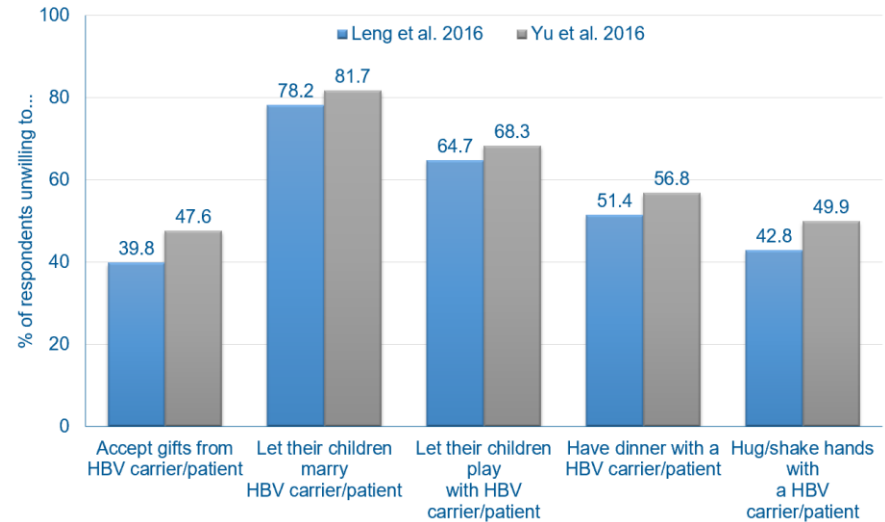
Some of the most pronounced examples of stigma were reported in two studies (that used the same five questions) conducted in rural adults or rural immigrants to a major city in China. In these two studies 43% and 50% of respondents were unwilling to hug or shake hands with someone with HBV and 78% and 82% of respondents were unwilling to let their son/daughter marry someone with HBV (Figure 2).

Fear of contagion was frequently identified as being a key underlying cause of stigma, and this was frequently postulated to be related to lack of knowledge around transmission routes. For example, in studies in China and Vietnam 73% and 55% of respondents, respectively, believed that HBV could be spread by sharing food or utensils.

Institutional stigma[†] directed towards people infected with HBV was believed to be more common in Asia than in North America. Several studies in Asian populations reported that people believed that being infected with HBV may lead to them being denied healthcare or employment opportunities.

Stigma from healthcare professionals

Two studies examined HBV-related stigma exclusively in healthcare professionals. In one study in dental students in Latin American countries, attitudes towards people infected with HBV were generally positive, but approximately 15% objected or strongly objected to treating patients infected with HBV. In another study in HCPs in China, attitudes towards patients with HBV were found to be more favorable compared with patients with HIV. For example, a significantly higher proportion of HCPs were willing to work with or socialize with people with HBV infection compared with people with HIV infection.

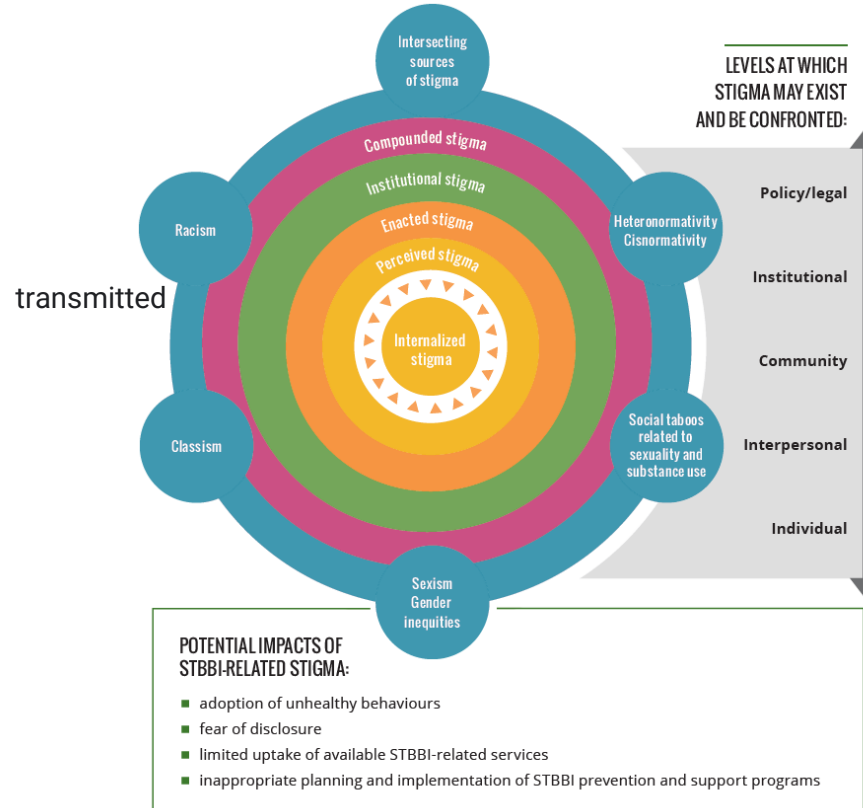


The Nature & Impact of Stigma in Patients with Chronic Hep B: A Systematic Literature Review

Conclusions

- To date, published studies on HBV-related stigma have predominantly been conducted in Asian or Asian immigrant populations and data from Western Europe are lacking
- Stigma directed towards people infected with HBV is common in Asian countries and can negatively impact many aspects of everyday life as well as educational and employment opportunities. HBV-related stigma in other regions including North and South America and Europe is not as well characterized
- Despite the availability of a vaccine, fear of contagion is a key driver of stigma, which in some studies was attributed to a lack of knowledge around transmission routes
- Clinical consequences of stigma could potentially include an unwillingness to seek testing, which in turn could lead to a delay in treatment for those patients requiring treatment as well as a risk of onward transmission in patients remaining unaware of their HBV status

Sexually and blood-borne infection (STBBI)



Takeaways

1. Primary impacts: the direct psychosocial impacts on the person living with CHB caused by the disease;
2. Secondary impacts: the impact on the affected person caused by the response from society (e.g., family members, healthcare providers, and community and government institutions);
3. Tertiary impacts: the harms associated with an affected person's response to societal stigma and discrimination.

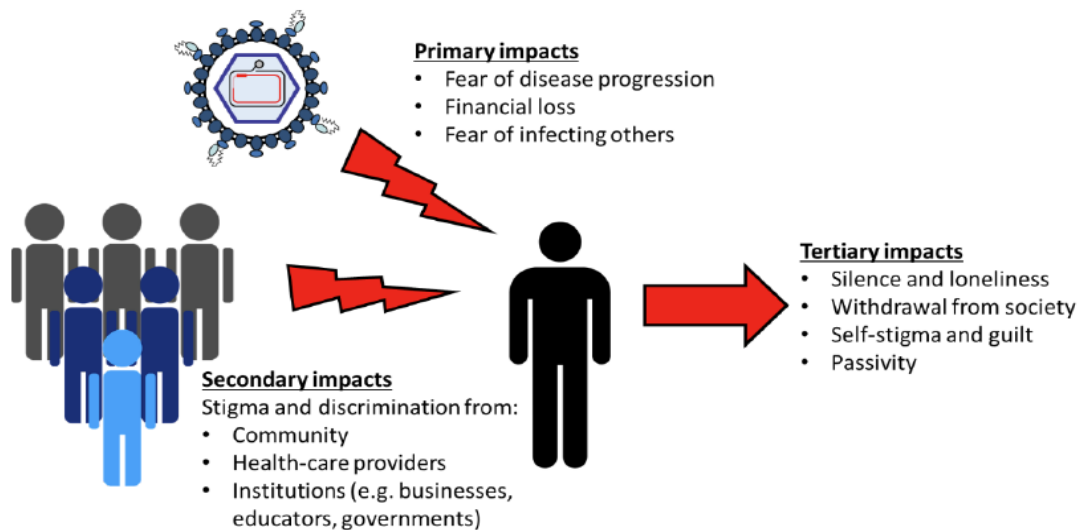


Figure 1. An overview of the psychosocial impacts of HBV infection on an individual living with CHB.

Thank you



- HBV-TAG partner Dr. Ira Jacobson
- HBV-TAG organizing staff
- Hepatitis B Foundation
- Chari Cohen, Kate Moraras, Catherine Freeland: HBF
- Janssen Research Team
- Scott Cotler MD
- Thomas Tu MD PHD