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Uncovering the silent burden of stigma: lived experiences of individuals with chronic hepatitis B infection

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Conclusions

Experiences of **stigma associated with chronic HBV infection** (internalized, social, institutional) were **highly pervasive**, indicating a **need to minimize** patient experience of stigma

To address the underlying burden of stigma on individuals with chronic HBV infection, **reducing internalized stigma would be most impactful**, as this was most common and most bothersome

Stigma associated with **social experiences** was also highly reported (e.g., interactions with HCPs, romantic partners, family), highlighting the value of educating others to minimize experiences of stigma

People with chronic hepatitis B often face stigma from themselves, others, and institutions. The first is the most common and harmful, so reducing it could greatly help. Social stigma from interactions with doctors, partners, or family is also frequent. Educating others about hepatitis B could help reduce these negative experiences.

Background

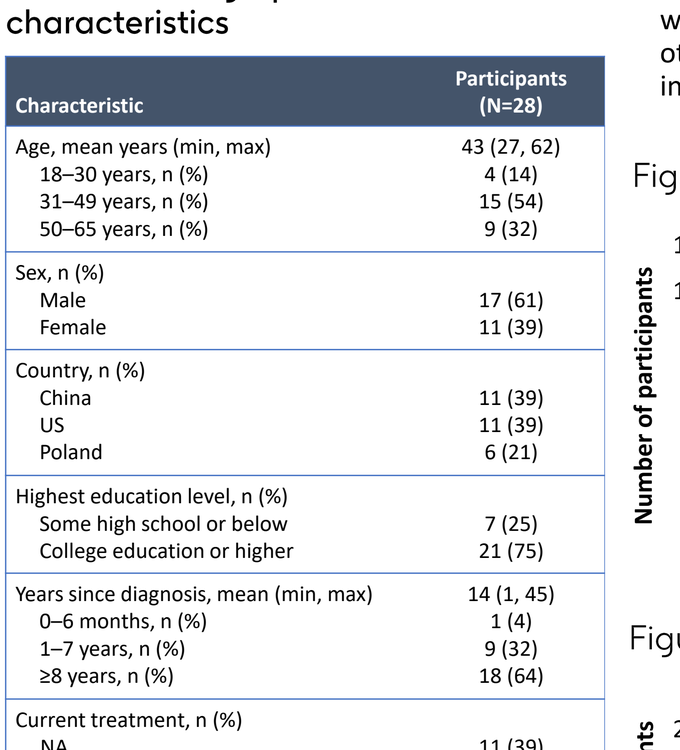
- Chronic hepatitis B virus (HBV) infection is a major global health issue, affecting 254 million people worldwide[1]
- Stigma related to chronic HBV infection is highly pervasive,[2] and individuals may experience negative self-beliefs, isolation, and discrimination, which significantly impact their health-related quality of life (HRQoL)[3–6]
- This study aimed, from a patient perspective, to understand current experiences and impacts of stigma associated with chronic HBV infection

Objectives

- To **understand the patient perspective** of how stigma, in relation to having chronic HBV infection, impacts the lives of patients
- To **summarize** the patient experience of stigma in a **patient-centric conceptual model**

Study design

Figure 1: **Overview of study methodology**



**Study initiation was followed by study protocol and associated document development, which were translated into Simplified Chinese and Polish; †ethical approval was obtained from a centralized Institutional Review Board covering US, China, and Poland*

Figure 2: **Eligibility criteria**

- Male or female aged ≥18 years
- Confirmed diagnosis of HBV infection for >6 months (i.e., chronic HBV infection)
- Speaks English (for US), Mandarin (for China), or Polish (for Poland) and is able to read, write, and fully understand the language
- Willing and able to provide written or electronic informed consent
- Able to participate in a 60-minute interview

- Confirmed diagnosis of decompensated cirrhosis and/or liver cancer
- Currently enrolled in a clinical trial
- Unwilling or has a physical, behavioral, or psychiatric condition that may affect ability to participate in the study and/or provide consent

The same eligibility criteria were used across all countries (US, China, and Poland). To ensure a range of clinical and demographic characteristics, sampling quotas were applied for sex assigned at birth, age, race (US only), education level, location of primary home, time since first diagnosed with HBV, and treatment type

- Qualitative, semi-structured, concept elicitation interviews of ~60 minutes were conducted to discuss participants' experience of stigma
- All interviews were conducted by trained interviewers in local languages and were audio-recorded, transcribed verbatim, and translated to English (if necessary)
- Qualitative analysis of interview data was conducted using Thematic Analysis methods. Concepts of interest were also categorized based on the following:

Spontaneous concept	• Concept first elicited spontaneously by participants following open-ended questions
Probed concept	• Concept first reported by participants when directly asked about the concept by the interviewer
Internalized stigma*	• Stigma felt by people on an individual level; includes anticipation of social rejection or negative stereotyping due to living with HBV
Social stigma*	• Stigma that involves the endorsement of negative preconceptions or stereotypes by social groups
Institutional stigma*	• Stigma that exists at a system-wide or policy level

**Participants did not explicitly describe the type of stigma experienced. Where it could be determined, participants' descriptions of overall stigma were categorized into stigma type according to Smith-Palmer et al. (2020)[4]*

Results

Table 1: **Demographic and clinical characteristics**

Characteristic	Participants (N=28)
Age, mean years (min, max)	43 (27, 62)
18–30 years, n (%)	4 (14)
31–49 years, n (%)	15 (54)
50–65 years, n (%)	9 (32)
Sex, n (%)	
Male	17 (61)
Female	11 (39)
Country, n (%)	
China	11 (39)
US	11 (39)
Poland	6 (21)
Highest education level, n (%)	
Some high school or below	7 (25)
College education or higher	21 (75)
Years since diagnosis, mean (min, max)	14 (1, 45)
0–6 months, n (%)	1 (4)
1–7 years, n (%)	9 (32)
≥8 years, n (%)	18 (64)
Current treatment, n (%)	
NA	11 (39)
Untreated	7 (25)
Other treatment*	5 (18)
Peg-IFN	3 (11)
NA & other treatment	1 (4)
NA & Peg-IFN	1 (4)
Comorbid conditions, n (%)	
Yes	8 (29)
No	20 (71)

**Other medications included antiviral medication not specific for chronic HBV infection (n=4) and liver protecting enzymes (n=1). Stigma related to taking treatments for chronic HBV infection was still explored during the interviews*
NA, nucleos(t)ide analog; Peg-IFN, pegylated interferon

- All participants described experience of **internalized stigma** (n=28/28; 100%), reporting negative self-beliefs or worry about being judged by others due to their HBV infection (**Figure 3**)
- Most participants (n=22/28; 79%) described **social stigma** experiences, including other people endorsing negative stereotypes and being treated differently due to HBV infection (**Figure 3**)
- Experiences of **institutional stigma** (n=16/28; 57%) were most common in China and Poland, with participants reporting being treated differently due to unfavorable institutional policies and/or laws (**Figure 3**)
- Concepts related to social functioning (n=28/28; 100%), emotional wellbeing and HBV transmission (n=27/28; 96% each) were most frequently reported (**Figure 4**); most participants reported these concepts spontaneously

Figure 3: **Stigma experiences were found to have widespread impacts**

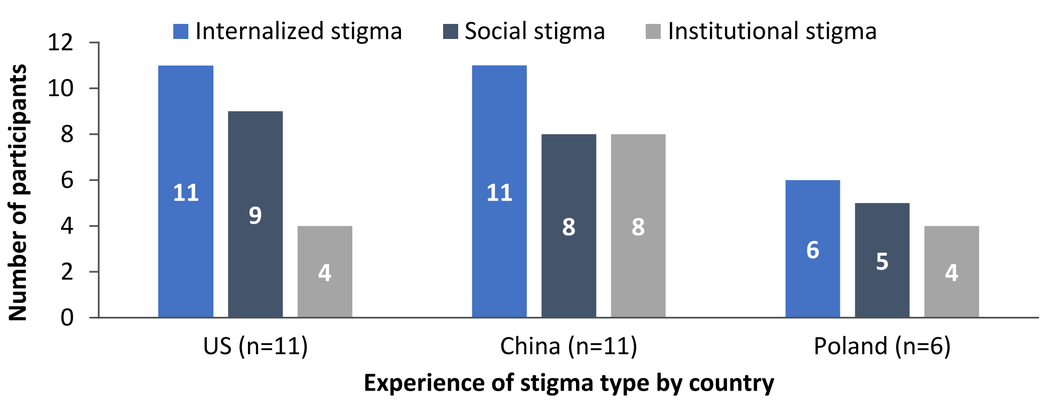
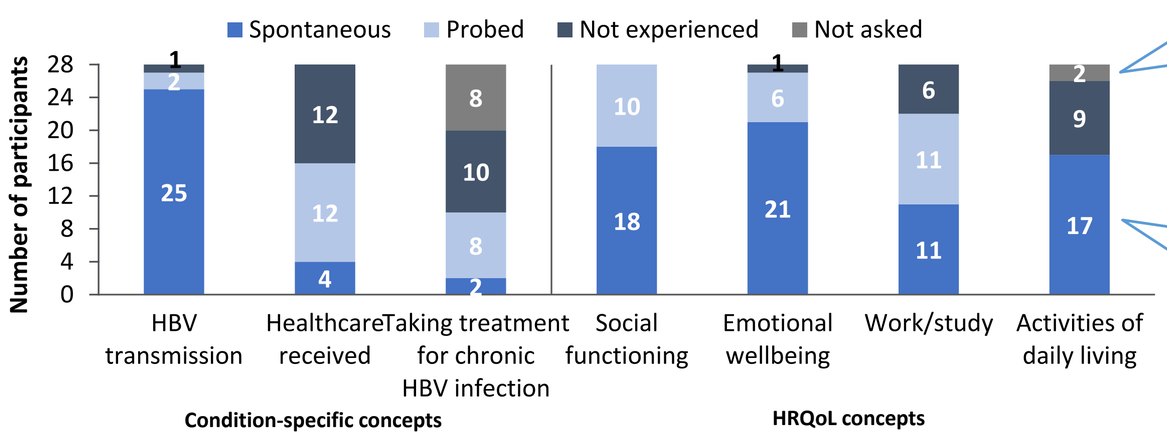


Figure 4: **The impact of stigma was extensive and affected many aspects of life**



Concept: HBV Transmission

"…And well, this person treated me like I had some strange sexual relationship with someone."

Concept: Social Functioning

"…It's just most difficult to find a partner who would show understanding towards such a person."

Figure 5: **Conceptual model of the patient experience of stigma associated with HBV infection**

Internalized stigma (n=28/28, 100%)
Social stigma (n=22/28, 79%)
Institutional stigma (n=16/28, 57%)

HRQoL concepts

Social functioning (n=28/28, 100%)
- Concerns about disclosing diagnosis (n=26)
- Romantic relationships negatively affected (n=22)
- Decreased socialization (n=20)
- Family relationships negatively affected (n=13)
- Friendships negatively affected (n=9)
- Intimate relationships negatively affected (n=9)

Work/study (n=22/28, 79%)
- Decreased career opportunities (n=17)
- Relationships with coworkers negatively affected (n=14)

Emotional wellbeing (n=27/28, 96%)
- Negative feelings about oneself (n=20)
- Anxious/worry (n=19)
- Sad/low mood (n=17)
- Fear (n=16)
- Frustration/anger (n=5)
- Shock/disbelief (n=2)

Activities of daily living (n=17/26, 65%)
- Avoiding sharing food and drink (n=14)
- Increased hygiene maintenance (n=4)
- Attending cosmetic appointments (n=2)

Condition-specific concepts

HBV transmission (n=27/28, 96%)
- Others' lack of understanding of how HBV is transmitted (n=27)
- Concerns about risk of passing on HBV to others (n=21)
- One's own understanding of how HBV is transmitted (n=17)

Healthcare received (n=16/28, 57%)
- HCPs behaving negatively/judging participants (n=8)
- Participants' perception of feeling judged by HCPs (n=8)
- Unfavorable healthcare policies/practices (n=3)

Treatment for chronic HBV infection (n=10/20, 50%)
- Negative perception of taking treatment (n=8)
- Being reminded of their diagnosis (n=2)

Icons represent the type of stigma reported at the domain concept level and are displayed in order of frequency (most to least associated). Bold headings in white indicate domain-level concepts reported by participants. Denominators represent the number of participants asked about experiences of stigma related to the HRQoL or condition-specific concept. Bulleted text indicates specific concepts reported by participants. Participants often reported more than one concept per domain. HCP, healthcare professional

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- On behalf of all authors, an audio recording of the original poster was prepared by Shannon Keith (employee of GSK)
- **SK, JD** and **PWG** are employees of GSK and hold financial equities in GSK. **VG** was an employee at GSK at the time of the study. **VS**, **MA**, **KF**, and **LG** are employees of Adelphi Values Ltd., a health outcomes agency commissioned to conduct research by companies in the pharmaceuticals industry. Adelphi Values received funding from GSK to conduct the research summarized in this publication

SCAN ME — AUDIO FILE

Digital poster (left)
Narrated summary (right)

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