

Correlates of Hepatitis B Virus-related Stigmatization Experienced by Asians: A Scoping Review of Literature

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ABSTRACT

Objective: Although remarkable progress in the pharmacological components of the prevention and treatment of hepatitis B virus (HBV) and liver cancer has been achieved, HBV-related stigma is recognized as a major barrier to HBV management. The purpose of this Revised Social Network Model (rSNM)-guided review was to examine the existing research literature about HBV-related stigma among Asians and Asian immigrants residing in other countries. **Methods:** A scoping review of literature was conducted to determine the depth and breadth of literature. Totally, 21 publications were identified. The review findings were linked with the concepts of rSNM to demonstrate how individual factors and sociocultural contexts shape and affect the experience of HBV-related stigma. **Results:** Most studies were quantitative cross-sectional surveys or qualitative methods research that had been conducted among Chinese in China and

in the USA. The three concepts in rSNM that have been identified as important to stigma experience are individual factors, sociocultural factors, and health behaviors. The major factors of most studies were on knowledge and attitudes toward HBV; only three studies focused on stigma as the primary purpose of the research. Few studies focused on the measurement of stigma, conceptual aspects of stigma, or interventions to alleviate the experience of being stigmatized. **Conclusions:** The scoping review revealed the existing depth and breadth of literature about HBV-related stigma. Gaps in the literature include lack of research address group-specific HBV-related stigma instruments and linkages between stigma and stigma-related factors.

Key words: Asian, barriers to health services, hepatitis B virus, Revised Social Network Model, scoping review, socioculture, stigma

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Introduction

Although Asian Americans are at lower risk for the most prevalent cancers, such as breast, lung, and colon cancers, experienced by most non-Asian Americans, they experience a significantly higher prevalence of chronic hepatitis B virus (HBV) infection and the subsequent development of hepatocellular cancer.^[1,2] Asian people with the HBV infection usually become infected during birth or from close family contact during early childhood and are at greater risk of developing long-term complications from the infection approximately 20 years earlier than people who become infected during adulthood.^[3-5] Findings from studies of Asian Americans indicate that the prevalence of chronic HBV infection ranges from 4% to 15%,^[1,2,6,7] which is more than 30 times the rate of 0.11% for non-Hispanic Whites.^[8] Furthermore, HBV is responsible for 75%–90% of primary hepatocellular carcinoma cases worldwide.^[8,9]

Due to the remarkable progress of the pharmacological prevention and treatment of HBV and liver cancer, great strides have been made in HBV and liver cancer management in the last three decades.^[2,3] However, results of studies of HBV and other infectious diseases point to the fact that the health-related stigma associated with these diseases has a direct negative impact on quality of life as well as the process of health-care delivery and medical decision-making.^[10-13] There is a long history of social discrimination against patients with such infectious diseases as leprosy, tuberculosis, and HIV.^[10-13] Research findings have revealed that people living with infectious diseases frequently are marginalized and experience considerable stigmatization.^[10-12] Hepatitis carriers have been described as modern-day “lepers”^[14] or “AIDS,”^[15] and individuals with HBV as well as their families have felt ashamed about having HBV.^[14]

In his seminal work, Goffman initially defined stigma as “the situation of the individual who is disqualified from full social acceptance” (p. 9).^[16] As the work about the concept of stigma has evolved, theorists and researchers have concluded that stigmatization not only applies to the stigmatized person but also manifests in the social context that defines an attribute as devaluating^[17] and discriminating.^[18] The devaluation of one’s social identity can be a major cause of the individual’s low self-esteem, particularly in his or her family.^[14,15,18] Moreover, health-related stigmatization often results in social and financial marginalization and withholding of treatment or denial of services,^[10,19] thereby violating the human rights of people with the HBV infection.

HBV-related stigmatization may occur at family, community, or institutional level and may be perceived or expressed visibly or invisibly. Research that informs our understanding of the attributes and the consequences of HBV-related stigma is important. However, there are no literature reviews evaluating the effect of stigmatization related to HBV infection among Asians. Therefore, the purpose of this paper is to report the results of a Revised Social Network Model (rSNM)-guided scoping review designed to examine the existing research literature about HBV-related stigma among Asians and Asian immigrants residing in other countries.

Conceptual model

The rSNM was selected to guide our understanding of how different sociocultural contexts shape and affect HBV-related stigma experiences. The concepts of this conceptual model are individual factors, sociocultural factors, health behavioral factor, and illness experiences. Individual factors account for person-centered influences such as knowledge, attitudes, or health belief. Sociocultural factors refer to characteristics including demographic, social, and cultural settings that form the background for people’s lives. Health-related behaviors are action taken by a person which affect his or her health status.^[20,21] Illness experience refers to the individual’s experience of HBV infection, and HBV-related stigma is considered a part of the HBV illness experience. Stigmatization and stigma-related factors were extracted from the studies, and the findings were categorized as stigma experiences (such as social exclusion or discrimination) that caused from individual and sociocultural factors and resulted in health behavioral changes. These linkages are found in the results section of this paper.

Methods

A scoping review of literature was conducted to determine the depth and breadth of literature about HBV-related stigma. A scoping review is based on iterative, conceptual, and interpretative approaches that encompass both empirical and conceptual literature about broadly framed questions. A scoping review emphasizes the importance of developing a critique based on the relevance, credibility, and contribution of evidence rather than by rigidly determined methodological considerations of analysis and synthesis that is a hallmark of other types of systematic reviews of literature.^[22,23] We identified two research questions for our scoping review: (1) What is HBV-related stigmatization? And (2) What are the correlates of HBV-related stigmatization among Asians?

Identifying relevant studies

To identify studies as comprehensively as possible, we searched for research evidence not only from electronic databases but also from the reference lists of all retrieved articles. Furthermore, a Google Scholar search and a search of the websites of several HBV-related organizations, including the WHO and the Hepatitis B Foundation were conducted.

Our electronic searches encompassed literature published between 1988 and 2016 and were conducted using PubMed, Medline, the Cochrane Library, the Cumulative Index to Nursing and Allied Health Literature, Health and Psychosocial Instruments, PsycINFO, SocINDEX, and the Educational Resources Information Centre. The search terms were “stigma* or stigmatization or

marginalization or shame AND hepatitis B AND Asia,” “stigma* or stigmatization or marginalization or shame or discrimination AND hepatitis B AND (various Asian countries).”

Inclusion criteria in search of both qualitative and quantitative studies were: (1) published as full text in the English language; (2) included Asian Americans or people from various Asian countries; (3) all age groups; (4) focused on HBV patients, families, communities, and health care providers; (5) focused on HBV-specific stigma.

Study selection

Figure 1 is a flow diagram of the search and selection of papers for the review. Although scoping review methodology does neither limit the reviews to research trials nor require quality assessment, we decided to carefully

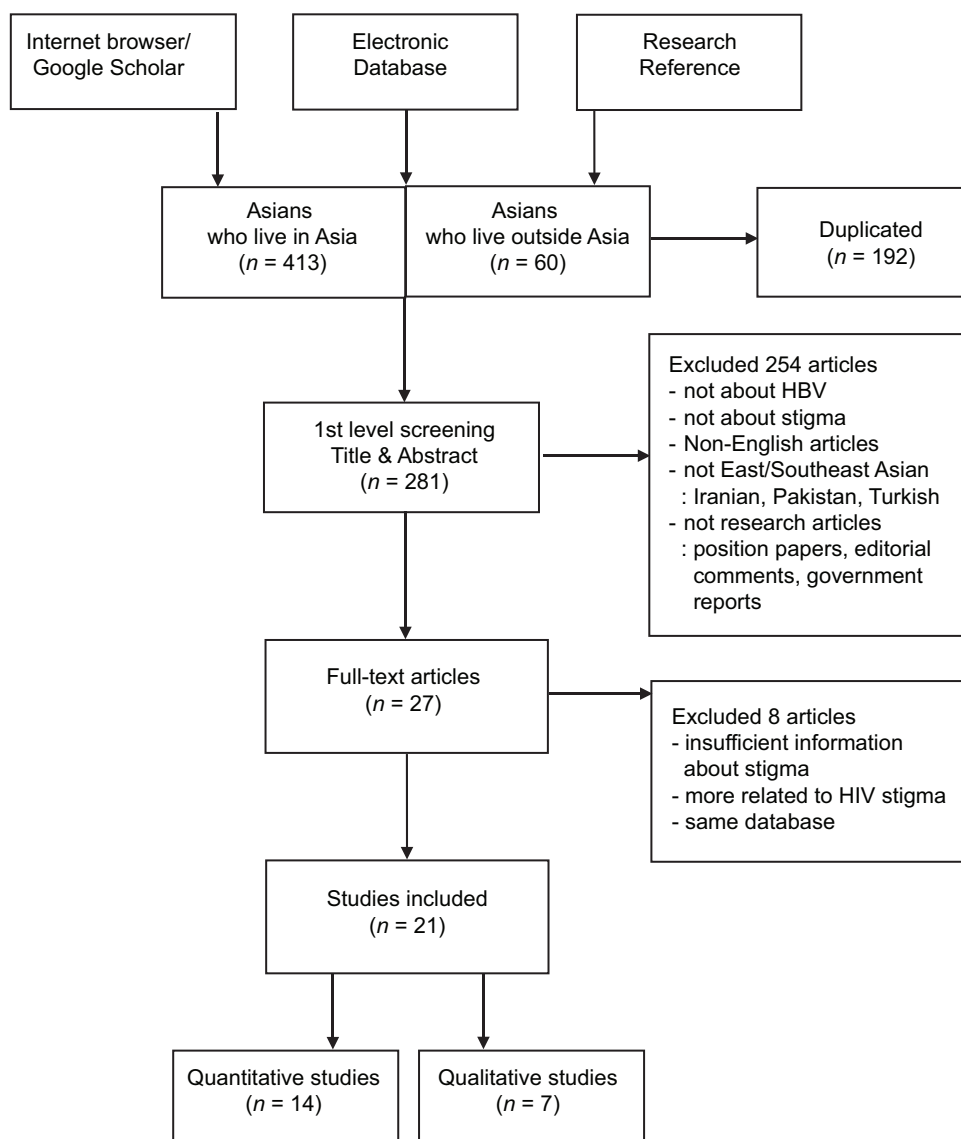


Figure 1: Scoping review flow diagram

develop a selection process. Our initial perusal of the citations indicated that our search strategy yielded a large number of irrelevant studies. For example, we found many search results for HIV and HCV infections-related stigma. However, we did not want to filter out these articles in case, some of the articles focused on coinfections of HBV. Titles and abstracts were reviewed by two independent reviewers (Haeok Lee and Deogwoon Kim) to determine eligibility based on the inclusion criteria. Duplicated papers and papers that were commentaries, summary reports, or media reports were excluded. Full-text articles were obtained for 21 papers and were read in full by three authors (Haeok Lee, Jin Yang, and Deogwoon Kim).

Process of scoping: Narrative review and charting data

Based on preliminary trial charting and sorting according to key concepts/factors and themes, the literature was categorized according to the aims of the study, the type of study design, the study population, stigma definition, and stigma-related findings.

Collecting and summarization

The findings of the scoping review of literature are documented in Tables 1 and 2 and in the narrative text. A descriptive-analytical method was utilized to present a narrative account of the existing literature. The tables include the distribution of studies geographically, research methods, definition and measures used, participants, and dimensions of stigma or stigma-related factors; the studies are listed in the chronological order of publication date, from the most recent publication to the earliest. Categorization of findings was performed by the authors (Haeok Lee, Jin Yang, and Deogwoon Kim) and checked, and discrepancies were resolved through discussion among the three authors (Haeok Lee, Jin Yang, and Deogwoon Kim). Data charting tables [Tables 1 and 2] were developed to sort the extracted data and included charting of key features, and literature review was organized based on rSNM. For example, recording information about the dimension or definition of stigma or correlates of stigma or the impact of stigma on health or stigma intervention so that the findings were more contextualized and more understandable to readers.^[22] Moreover, the findings of the literature review were organized and are depicted in Figure 2 based on rSNM to help better understanding of HBV-related stigma phenomenon.

Results

Research methods

Table 1 presents the quantitative studies and Table 2 presents qualitative studies. As can be seen by reviewing both tables,

most studies were cross-sectional surveys that had been conducted in China, Hong Kong, Japan, Korea, Malaysia, Taiwan, USA, Canada, and Australia; the majority of the studies was conducted outside Asia. As shown in Table 2, various qualitative methods were used, including open-ended interviews, focus groups, grounded theory, semi-structured and in-depth interviews, and ethnography. Most studies focused on knowledge of and attitudes about HBV. Only three studies^[24-26] focused on stigma as the primary purpose of the research. In the cross-sectional surveys reviewed, only three studies^[24,26,27] included dimensions of stigma. The other studies did not include an explicit definition of stigma or a theoretical frameworks that might have guided the research, including the way in which stigma was measured. HIV- or HCV-related stigma, rather than, HBV-related stigma, was the main focus of the studies that included the coinfections of HIV, HCV, and HBV. Only two articles report of experimental research of the effects of interventions on overall management of HBV; both studies were conducted in the USA and by the same research group.

Participants

Participants were convenience samples of patients utilizing Asian-serving clinics, people who were members of Asian serving community organizations, or people attending community events. Chinese people in China and in the USA were the most studied groups.^[24-35] The participants were HBV-infected patients, members of the general community, health-care providers, or community leaders [Tables 1 and 2]. All participants were adults. Only seven studies^[24,26-28,31,34,36] included a report of the response rate and one study^[34] included a report of response rates below 40%. None of the researchers used online recruitment methods.

Stigma experiences

Literature revealed that HBV-related stigma is subjective and internalized, perceived, or experienced by individuals, in interpersonal interactions (or face-to-face) or in the larger society. A general consensus exists about the definition of stigma as a negative perception with fear of rejection at both personal and family levels and which cause harm to both the family and the society. Stigma prevented both individuals and their family members to disclose the presence of HBV infection because they feared discrimination from the society.^[15,25,28,31-34,37,38] Reports of indicators of stigma ranged from 24%^[36] to 70%.^[39] In most studies, stigma was regarded as a dimension of knowledge of and/or attitude about HBV. Community members, community leaders, health care providers,

Table 1: Summary of quantitative studies

Authors/Year/ Geographic region	Study design	Sample	Stigma definition	Stigma-related variables/Other constructs	Stigma-related consequences/Findings
Maglalang <i>et al.</i> , 2015 CA, USA	Evaluation of San Francisco Hep B Free (SFHBV) intervention	Cantonese or English- speaking community dwellers (Asian) 40 in 2013	"Saving face"	A cultural norm of maintaining a positive reputation that is seen as imperative for social acceptance and economic mobility	To increase awareness and to motivate people to seek treatment or screening for HBV Participants' awareness of HBV was impacted by SFHBV campaign.
Yu <i>et al.</i> , 2015 China	Survey design	Community dwellers 6,538 from 42 villages	Yes: negatively judging and unfairly treating. A part of attitude toward HBV patients and carriers	Fear of infection Knowledge about transmission HBV vaccination status	Tried to avoid: accepting gift hugging/shaking hands having dinner together children playing together children marrying with HBV infected person
Carabez <i>et al.</i> , 2014 CA, USA	Descriptive survey design	HBV infected patients 60 Chinese 27 Japanese 17 Korean 11 Vietnamese 9 Filipino 10 mixed Asian	No	Knowledge Fears of liver cancer	Stigma is not a main purpose. Fears of transmission to loved ones and social stigma
Dahl <i>et al.</i> , 2014 Australia	Prospective design	55 HBV patients 13 Chinese 5 Malaysian 4 Vietnamese 3 Filipino 2 Burman Others	No A part of knowledge	Knowledge	95% felt comfortable to tell a family member. 35% felt comfortable to tell friends and coworkers.
Shi <i>et al.</i> , 2013 China	Survey design	724 College students	Yes: Link & Phelan's definition.	HBV blood test results HBV-infected family member or friend	Labeling Stereotyping Separating Discrimination
Eguchi & Wada, 2013 Japan	Cross-sectional design	3,129 workers	No A part of attitude 2 items to measure	Attitudes toward HBV- and HCV- infected colleagues	Had prejudiced opinions Avoided contact with infected colleagues Knowledge was associated attitudes.
Cotler <i>et al.</i> , 2012 IL, USA	Survey Design	201 Chinese HBV carriers 16% HBV vaccinated 36% 11/32 had family history of HBV	Yes: 5 domains; negative perception, social isolation, fear of contagion, healthcare neglect, workplace/ school stigma	HBV stigma: HBV carriers bring trouble to their families and harm others	70% believed that HBV carriers put others at risk. 62% agreed that HBV carriers should subsequently avoid contacting with others.
Li <i>et al.</i> , 2012 Canada	Survey Design	343 Chinese	Yes: Goffman's definition and the Toronto Chinese HBV Stigma Scale (20 items)	Knowledge	Fears of the consequences and contagiousness of HBV play a role in the development and perception of HBV stigma.
Maxwell <i>et al.</i> , 2012 CA, WA, DC, USA	Correlational Design	653 Vietnamese 260 Homing 493 Korean 329 Cambodian	No 1 item to measure	Knowledge Awareness Susceptibility Severity	38% Vietnamese, 55% Hmong, 47% Korean, and 70% Cambodian believed that people avoid people with HBV (stigma). Respondents with higher knowledge scores were more likely to agree that people avoid people with HBV (stigma).
Yoo <i>et al.</i> , 2012 CA, USA	Community intervention	23 individuals of Asian American community (community members, health care providers, community leaders)	No		HBV associating with "bad people" and "bad behavior"

(Continued).

Table 1: (Continued)

Authors/Year/ Geographic region	Study design	Sample	Stigma definition	Stigma-related variables/Other constructs	Stigma-related consequences/Findings
Guirgis <i>et al.</i> , 2011 Australia	Descriptive study	60 HBV patients 24 Chinese 3 Hong Kong 33 Others	No 1 item to measure	Perception of HBV	53% reported fear of discrimination/stigma.
Mohamed <i>et al.</i> , 2012 Malaysia	Cross-sectional design	483 chronic HBV patients 353 Chinese 109 Malaysian 12 Indian 9 Others	No A part of attitude	Knowledge Attitude toward HBV	69% worried about spreading virus to family members and friends. 34% felt embarrassed to disclose their disease status. 34% were against having HBV patients work in food industry.
Wang <i>et al.</i> , 2009 Taiwan	Cross-sectional design	328 college students 106 chronic HBV 113 susceptible 109 immuned	No	Knowledge Health belief Self-efficacy of HBV prevention	Afraid to disclose infection status to friends Afraid to acquire infection from infected friends
Lai & Salili, 1999 China	Cross-sectional and comparison design	90 mothers 30 with healthy children 60 with HBV-infected children	No A part of attitude	Parenting stress Attitudes toward HBV children	Mothers of healthy children disagreed with the idea of integrating HBV children into ordinary schools. They thought that HBV would be transmitted and HBV infected children are inferior having low self-esteem.

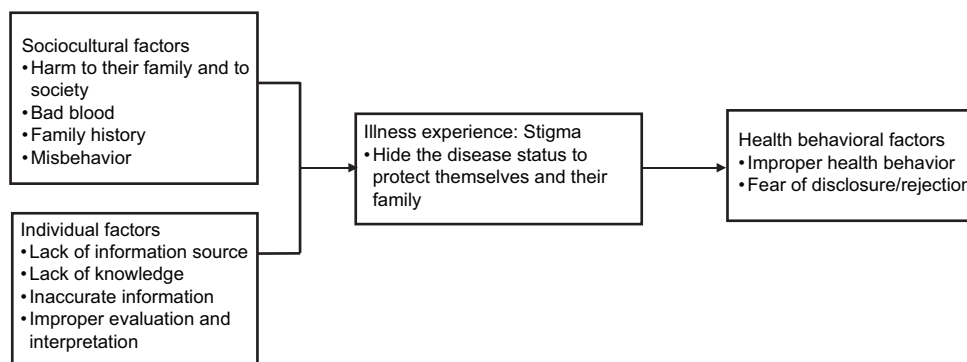


Figure 2: Conceptual framework for HBV-Related stigma

and college students were identified as groups who stigmatize the HPV-infected persons. Only two studies^[24,26] included multidimensional measures of stigma and only one study^[26] was a report of the development of stigma measures, including psychometric properties but only for Chinese Americans.

Public or societal stigma related to HBV infection status is commonly found in Asian countries and Asian communities in the US and has been perceived and/or experienced as social exclusion or discrimination. Stigma may be experienced when family or social norms are internalized. For example, in some qualitative studies, the participants perceived themselves as being referred to in terms such as having “bad blood” or having “bad gene” or “being contaminated” or “misconductedness.”^[15,37,40,41] This self-devalued quality of one’s social identity inflicts

damage on one’s self-esteem.^[15] Interpersonal or face-to-face stigma may be experienced through encounters with the family or through interpretation of family experiences. Despite the heterogeneity of Asian ethnicities, most Asian cultures have common several cultural values such as interdependence, collectivism, and family centeredness.^[15,42] Given the collective nature of Asian cultures, having HBV is a reflection on the family rather than the individuals, and families with an HBV-infected member may perceive or encounter public stigma or losing family face.^[15] The threat of social stigma may prevent people living with HBV from revealing their status to others.

The definition of HBV-related stigma found in the literature was varied reflecting the different perspectives of the stigma found in different sociocultural contexts and/or with different populations that were the focus of the particular

Table 2: Summary of qualitative studies

Authors/Year/ Geographic region	Design	Sample	Purpose	Categories or factors	Stigma-linked themes
Lee <i>et al.</i> , 2014 CO, Northeast, & MA, USA	Individual interview/Focus group interview	Community health leaders: 9 Koreans 14 Khmers	To explore factors influencing HBV and liver cancer prevention health behavior within the sociocultural contexts of CAs and KAs	Sociocultural Socio-medical Socio-linguistic Socio-resource Individual Health-related behavioral	Individual factor: perceived transmission of HBV as a “contagious” or “contaminant.” KAs tend to emphasize sanguinity and family history, whereas CAs blame the unhealthy environment during Khmer rouge era and in refuges campus
Ng <i>et al.</i> , 2013 Malaysia	Focus group interview	44 HBV-infected patients from an outpatient clinic	To capture the experience of people with chronic HBV when they were first diagnosed	Patients’ feelings, reactions, and coping strategy Patients’ needs	Individual factor: fear of being discriminated by or causing anxiety to their social contacts. “I didn’t dare to let anyone know. I was afraid that people will be scared of me. I only let my family know. Not even my friends know.” Health behavioral factor: “I can drink yours but you cannot drink mine.” “So we kept separate bowls, spoons, everything also separate.”
Philbin <i>et al.</i> , 2012 MD, USA	Focus group interview	58 Asian immigrants 20 Chinese 19 Korean 19 Vietnamese	To explore knowledge, awareness, and perceived barriers toward HBV screening and vaccination	Stigma Knowledge Awareness; Susceptibility Factors affecting screening and vaccination Cultural barriers to prevention Health care system	Stigma theme was repeatedly raised across groups as a barrier to liver cancer prevention. Health behavioral factor: accessing care was a potential problem from the perspective of stigma since it can make it more difficult to keep one’s status secret. Sociocultural factor: there were relatively high levels of discrimination from community. For example, afraid of having a pamphlet in their possession would make others think they were HBV carriers.
Russ <i>et al.</i> , 2012 CA, USA	Semi-structured interview	23 providers 17 HIV positive patients with HBV or HCV co-infection 7 Filipino 6 Chinese 3 Vietnamese 1 Indonesian	To identify barriers to care and treatment in API with HIV and without hepatitis co- infection	Stigma Individual and structural barriers to care	For both patients and providers, stigma was the most commonly recognized barrier to care. Stigma can create additional barriers for clients seeking ethnically/linguistically specific care and for providers within the Asian American community interested in filling this gap in care. Individual factor: co-infected patients may be willing to talk about their HIV status but tend to compartmentalize their conditions and avoid disclosing their hepatitis infection. Sociocultural factor: stigma associated with HIV and hepatitis co-infection in Asian community extends to the stigmatization of physicians who provide HIV services. Health behavioral factor: providers indicate that not only clients avoid providers who might be able to identify them but these clients also avoid places where they might be identified by members of their community.
Lee <i>et al.</i> , 2011 CO & Northeast, USA	Semi-structured face-to-face interview	18 Korean with HBV infection	To seek real-world data about factors influencing the recognition and management of HBV infection	Sociocultural meaning Layman’s construction of the cause Misunderstanding and cultural learning styles Personal and environmental barriers	The socio-cultural meaning of disease: the patients reported many negative perceptions and experiences in living with the virus since stigma related to HBV infection status is commonly found in Asian communities due to misunderstandings about the transmission route of HBV. Thus, patients hid the disease. Individual factors: perceived not just a blood- transmitted disease but a blood-borne disease; reluctant to share their condition with others who were not family. Sociocultural factor: HBV was socially perceived as “causing harm to family and to society.” People think HBV is a contagious disease. It is bad blood like AIDs. Afraid that if people know their conditions, they would not eat with them.

(Continued).

Table 2: (Continued)

Authors/Year/ Geographic region	Design	Sample	Purpose	Categories or factors	Stigma-linked themes
Wallace <i>et al.</i> , 2011 Australia	Face-to-face semi-structured interview/ focus group discussion	40 community health workers 20 HBV patients 6 Vietnamese 5 Chinese 3 Khmer 6 Others	To develop a comprehensive public health response to hepatitis B in Australia	Disclosure Clinical management Participants' beliefs and concerns about HBV infections	Selective disclosure: disclosure was not easy for all people that we spoke with. Some respondents talked of complex rules about disclosure for different friends and family members in different situations. The fear of rejection or stigma at a personal and community level was identified as an important issue that restricted individual disclosure. Sociocultural factor: the impact of chronic HBV diagnosis and subsequent disclosure of this information within some communities can lead to exclusion from family and community life. Health behavioral life: HCP noted less stigma related to HBV in comparison to other sexually transmitted diseases.
Lee <i>et al.</i> , 2010 Korea	Face-to-face interview	9 Koreans with HBV infection	To explore infected Korean's perspective's, knowledge, and experiences of living with a HBV diagnosis	I am just a carrier, no harm Experience of living with an invisible virus Misunderstanding and its impact on health and social life Management of chronic HBV	Misunderstanding and its impact on health and social life: the participants linked their infection to family history by identifying family members who were diagnosed with liver disease and died from liver cirrhosis or liver cancer. Sociocultural factor: "People think HBV is a contagious disease.. It is transmitted through food, a cup of alcohol, or other things. Like AIDS, people misunderstand and have a wrong view about HBV infection." "I am not at the stage I need to reveal my infection condition to others. I feel bad when sharing food with friends."

study. HBV-related stigma was reported by patients, community members, and health-care professionals. Based on the literature review, HBV-related stigma has been defined as a multidimensional concept including social, interpersonal, and personal stigma. It is a perceived and experienced (enacted) phenomenon and results from a perception of how others (including family members) view the stigmatized person and can result from and it related to poor health behavior.

The causes of stigma

The causes of stigma were attributed to both individual and sociocultural factors in various studies [Tables 1 and 2]. Maxwell *et al.* found that knowledge and awareness levels of HBV infection were associated with stigma across 4 community-based surveys from 38% to 70%.^[39] Fear of HBV infection is the most common cause of HBV stigma.^[24,27,33,35,38,43] A lack of knowledge and awareness of HBV often resulted in a misunderstanding of the disease and results in the stigmatization of one's own self or stigmatization of people infected with HBV.^[15,24,27-29,32,41] The findings of both quantitative and qualitative studies revealed that most Asian or Asian Americans including health-care providers stated that sharing of contaminated food and eating utensils was the most common route of HBV transmission.^[15,27,31-34,37] Between 38% and 70% respondents believed that HBV carriers put others at risk,

expressed their intention to avoid them, and supported their isolation.^[24,39] Similarly, HBV-infected participants expressed fears of transmitting the virus to loved ones through casual contact.^[43]

Furthermore, culture influences the meaning or beliefs that individuals attach to HBV and can cause stigma experiences.^[29,33,41] In Asian sociocultural context, HBV is often viewed as harmful to society or to the family, and HBV-positive status wrongly stigmatizes family members and increases the fear of "loss of face."^[15] A person who "loses face" can no longer function well in his or her social network and, for example, can influence other's beliefs about the social acceptance of an individual or his/her family for marriage or employment.^[35,38]

Health outcome of stigma

Participants in both qualitative and quantitative studies experienced HBV-related stigma both personally and socioeconomically. The stigma affected admission to certain schools or parental rejection at schools and resulted at a time in loss of employment.^[30,43] Another outcome is that HBV-related stigma on both personal and family levels acts as an impediment to marriage and having children.^[15,35] The findings of qualitative studies indicated that HBV-related stigma is a serious barrier to accessing services.^[25,33] It was found that HBV-positive individuals were more

likely to disclose to the family but reluctant to disclose their condition to friends and coworkers.^[28,32] Two studies reported that the individuals who did not disclose their HBV status to others reported higher perception of stigma.^[38,39] Only two quantitative studies included examination of the relation between HBV stigma and health care including blood screening and other health behaviors.^[26,27]

In summary, the review suggests that HBV-related stigma is a part of the illness experiences resulting from a perception of how others (including family members) view them. Stigma can also negatively affect the health and health behaviors [Figure 2]. The three concepts in rSNM that have been identified as important to the stigma experience are individual factors, sociocultural factors, and health behaviors and confirms that the way people perceive or respond to HBV is as much as a sociocultural process as it is a result of individual actions.

Discussion

Our findings point to the fact that stigmatization is caused by individual and sociocultural factors, and that stigmatization not only occurs for the HBV-infected person but also is manifested in a social context in which discrimination against or devaluation of both patients and family occurs. In addition, institutional disadvantages caused by societal stigmatization are placed on stigmatized persons creating barriers to their receiving HBV blood screening and HBV management. The studies in China confirmed that HBV-infected individuals are regarded by the society as having a disgraced moral status and are banned from the society including workplaces and schools.^[26,30,35] Clearly, we need to examine the experience of stigma not only among individuals with HBV infection but also among HBV-infected families and health-care professionals within their sociocultural contexts.

The outcomes of stigma for HBV-infected people are important to understand because they will become not only obstacles for liver cancer prevention and treatment of infected individuals but also risks for others. If infected individuals are not aware of their infection or misunderstand how HBV is transmitted, they will unintentionally infect others as well as not receive appropriate health management. The loss of family, friends, community, and health care and the loss of employment result in infected individuals feeling rejection, marginalization, and discrimination. For example, in China and Korea, there is pervasive discrimination against people who suffer from chronic HBV infection. HBV-infected children are frequently expelled from schools and adults fired from jobs.^[2] They are shunned by other community

members despite recent national antidiscrimination efforts.^[44,45] In a 2007 survey covering 10 major cities in China, hepatitis B was cited as one of the top three reasons for job discrimination.^[46]

The scoping review is a novel approach to provide a rigorous and transparent method for mapping areas of research including the volume, nature, and characteristics of the primary research. It allows us to identify the gaps in the evidence, summarizing and disseminating findings as Arksey and O'Mally claimed.^[22] The results of our scoping review of literature suggest that there is a great need for more research to increase our understanding of the phenomenon of stigma among Asian HBV-infected people and their family members. For example, the correlational and longitudinal evidence is now needed to establish linkage and causality between stigma and HBV and liver cancer management behaviors. This will open a new line of research in liver cancer prevention and HBV management that will benefit the substantially underserved and understudied Asians in both Asian countries and where Asian immigrants reside more broadly. Since HBV requires a relatively long course of treatment and regular screening, stigma constitutes an obstacle to continuing or remaining in treatment.^[33] Quantitative measures used in studies are largely attitude or knowledge scales or contain one item measuring the broad and general negative feeling toward HBV-positive people. Thus, to more accurately explore the sources and consequences of HBV stigma, it is imperative to develop a culture-specific multidimensional HBV stigma instrument. Data collected from the use of this instrument will prepare the way for effective HBV stigma interventions.

Both individual and community-level interventions to reduce the burden of HBV-related stigma are necessary in both Asian countries and where Asian immigrants reside. Given the deeply ingrained HBV-related stigma among many Asians in Asia, it is not surprising that many Asian immigrants remain reluctant to undergo testing or to seek medical attention for a positive test result even after moving to the USA or another Western country.^[33] Because avoidance of HBV testing and management is due largely to a lack of knowledge about the routes of HBV transmission and means of prevention as well as social stigmatization of the disease,^[15,33,40] it is imperative to develop and implement targeted group-specific public health educational interventions.

Conclusion

HBV-related stigma presents as a part of the HBV illness experience and is a perceived and experienced

multidimensional phenomenon and is a complex social process. It is likely to impede participation in health care. There are significant gaps in the literature. The majority of the studies included in our review were descriptive or cross-sectional. Studies of stigma from other infectious diseases revealed that different sociocultural contexts contribute substantial variation in the construction of stigma. However, only one study to date has focused on studying the HBV-stigma from the perspective of the Chinese subgroup of Asians.^[24] Future longitudinal and multi-Asian subgroup level research is needed and should be based on target-group-specific stigma definitions and measures as well as relevant theory. Thus, the development of a culturally relevant and acceptable psychometric instrument that measures HBV-related stigma and stigma-related factors among other Asians is a critical step for understanding the mechanisms that underlie relation between HBV-related stigma, culture, and health behavior.

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Conflicts of interest

There are no conflicts of interest.

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