BMJ Open Chronic Hepatitis B stigma in Ghana: a qualitative study with patients and providers

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ABSTRACT

Objective This study explored beliefs contributing to Hepatitis B stigma, and the ways in which Hepatitis B stigma manifests, from the perspectives of people with chronic Hepatitis B as well as healthcare providers in Northern and Southern Ghana.

Design We used an exploratory qualitative design with a purposive sampling technique. Face-to-face interviews and focus group discussions were conducted. Data were processed using QSR Nvivo V.10.0 and analysed using inductive thematic analysis.

Settings Participants were recruited from one tertiary and one regional hospital in Ghana between February and November 2017.

Participants Overall, 18 people with chronic Hepatitis B (PWHB) and 47 healthcare providers (primary care physicians, nurses and midwives) between the ages of 21 and 57 years participated in the study.

Results PWHB face stigma in their sociocultural context and the healthcare environment. Three main beliefs underlying stigma were found: (1) the belief that Hepatitis B is highly contagious; (2) the belief that Hepatitis B is very severe and (3) the belief that Hepatitis B is caused by curses. Stigmatisation manifested as avoidance and social isolation (discrimination). In healthcare settings, stigmatisation manifested as excessive cautiousness, procedure postponement or avoidance, task-shifting and breaches of confidentiality.

Conclusions Given the prevalence of incorrect knowledge, as reflected in the beliefs about Hepatitis B, we recommend public awareness campaigns that emphasise Hepatitis B transmission routes. Also, given the manifestations of the stigma in healthcare settings, we recommend the development and implementation of a continuing professional development programme on Hepatitis B and adjusted policy on Hepatitis B vaccination for Healthcare providers (HCPs).

INTRODUCTION

Hepatitis B viral (HBV) infection remains a public health challenge affecting approximately 248 million people worldwide.¹ Globally, about 887 000 deaths attributable to complications of Hepatitis B (ie, hepatocellular carcinoma and cirrhosis) were recorded in 2015.² Sub-Saharan Africa is

Strengths and limitations of this study

- This study is the first to document Hepatitis B stigma in Ghana.
- Triangulation of the data across settings as well as the inclusion of people with chronic Hepatitis B (PWHB) and healthcare providers (primary physicians, nurses and midwives) assisted in understanding and describing the phenomenon, and further ensured the trustworthiness of the findings.
- Although this study provided insight into the beliefs contributing to Hepatitis B stigma and the manifestations of stigma in Ghana, we recommend confirming these results quantitatively in a large representative sample of the Ghanaian population.
- We recognise the possibility of recall bias since the PWHB had lived with the disease for a period between 1 and 7 years.

disproportionately affected² as evidenced by the high HBV prevalence in the region.^{3–6}

Within the Ghanaian context, several studies have estimated Hepatitis B prevalence above 8%.^{3–12} In fact, the most recent prevalence estimate of Hepatitis B in Ghana is 12.3%.³ HBV transmission occurs through several means.^{1–13} In high endemic countries such as Ghana, Hepatitis B is predominantly transmitted perinatally.¹³ Other practices, including but not limited to, unsafe injections, blood transfusions, dialysis, needle stick injuries, intimate sexual contact and non-sexual contact are postulated as a vehicle for HBV transmission.¹³ Perhaps, challenges such as the high cost of testing and treatment, poor referral systems, a lack of HBV management guidelines and inadequate infrastructure for screening contribute to the high prevalence of Hepatitis B in developing countries, including Ghana.^{14–16}

Generally, conditions with some risk of transmission are associated with stigma.^{17–18} This is well reported for conditions such as Tuberculosis and HIV.^{19–22} Similarly, people with chronic Hepatitis B (PWHB) are likely

to be stigmatised.^{23–29} Goffman,³⁰ in his seminal work, described stigmatisation as a socially and culturally constituted process whereby a person is first labelled as different and then devalued, leading to status loss and discrimination. Link and Phelan³¹ also outlined three main motivations for stigmatisation namely exploitation and domination (keeping people down), enforcement of social norms (keeping people in) and avoidance of diseases (keeping people away). Exploitation and domination occur when a group of people dominate or exploit another by virtue of their wealth, power and high social status. Enforcement of social norms centres on written and unwritten rules that people are expected to follow and those who violate these norms are stigmatised.³¹ Because Hepatitis B is an infectious disease, the third motivation for stigmatisation, disease avoidance, is most likely. This is supported by evidence from Canada and Pakistan showing that PWHB experience stigma because of the perceived infectiousness of HBV.^{32–33} However, research also supports the contention that stigmatisation of PWHB may be motivated by a desire to enforce social norms as Hepatitis B has been reported to be considered the consequence of promiscuous behaviour.^{29–34–35} Further, given that HBV can be transmitted through intimate sexual contact, the enforcement of social norms as a motivation for stigmatisation could be particularly relevant in Ghana, where the majority of the population are Christians and Muslims who disapprove of premarital sex.³⁴ In addition, a lack of knowledge about HBV routes of transmission has been found to also contribute to Hepatitis B stigma in other locales, such as China.³⁶

The stigmatisation of PWHB manifests in many ways. Previous studies conducted outside of Ghana have reported social exclusion, problems with close relations including friends and families and loss of employment as some of the ways in which Hepatitis B stigma presents.^{33–35–37} Hepatitis B stigmatisation also occurs across a number of settings and contexts, including healthcare settings.^{38–39} For example, Wada and colleagues³⁸ found that some healthcare providers in Japan were reluctant to care for patients with chronic Hepatitis B due to fear of infection.

The stigmatisation of PWHB has substantial consequences. It has been found to create an environment of secrecy and denial, can lead to depression and can be a barrier to healthcare seeking, including screening and treatment.^{28–32–39–41} Additionally, fear of being stigmatised, rejected and discriminated against has been found to motivate PWHB to conceal their positive status from family and friends,^{25–39–42–43} and non-disclosure of HBV status can contribute to further infections.⁴⁴ Stigmatisation can also deter people at risk for HBV infection from getting tested, obtaining treatment when eligible, and from seeking assistance for risk reduction.^{28–32–41}

Given the high prevalence of Hepatitis B in Ghana,³ and the paucity of evidence on Hepatitis B stigma in Ghana, this study sought to explore beliefs contributing to Hepatitis B stigma, and the ways in which Hepatitis B

stigma manifests, from the perspectives of PWHB as well as healthcare providers in Northern and Southern Ghana. Understanding this phenomenon is important as it can inform the design of effective Hepatitis B and stigma prevention interventions as well as Hepatitis B policies in Ghana and beyond.

METHODS

Study design

An exploratory qualitative design was used to explore the perspectives of PWHB and HCPs on Hepatitis B stigma in Ghana. This design was deemed best suited for this study because there is very limited documented evidence on Hepatitis B stigma in Ghana.⁴⁵ This study is part of larger research project focusing on Hepatitis B stigma. In this article, we report only on the findings that pertain to manifestations of stigma and the beliefs that underlie those manifestations.

Study setting

The study was conducted in two public health facilities in Ghana. Ghana is a tropical country on the West coast of Africa.⁴⁶ According to the most recent census, the population of Ghana was about 28 308 301 in 2016.⁴⁷ There are 10 administrative regions in the country. Each of the regions has a regional hospital which serves as a referral centre for the district hospitals. Also, the country has three main teaching hospitals.⁴⁸ A special clinic for patients with liver conditions, including Hepatitis B, are run at the tertiary hospitals whereas PWHB are mostly treated as outpatient cases in regional hospitals. One tertiary hospital in the South and one regional hospital in the North were selected for the study. The selection of the study areas was based on the differences in terms of tradition and culture in the selected regions. People from the Northern region tend to uphold to their tradition and culture to a greater extent than people in the South where urbanisation seems to impact the preservation of tradition and culture.

In Ghanaian society, people tend to attach beliefs to the cause of illnesses depending on their religious affiliation. For example, Christians and Muslims recognise God as the one who controls life events and has the power to deliver people from bad situations including illnesses. Similarly, those with traditional beliefs also tend to attribute the cause of unusual events including illness to consequences of a sin against the gods.

Study population

We recruited PWHB and HCPs including primary physicians, nurses and midwives in both Northern and Southern Ghana for the purposes of data source triangulation. Ensuring triangulation was imperative to understanding the Hepatitis B stigma comprehensively and to further validating information obtained from the participants.⁴⁹ Inclusion of HCPs was deemed appropriate as they play an important role in the provision of care to

PWHB. Also, given that stigma is experienced by PWHB in clinical settings, including the perspectives of HCPs was considered important.

Participant eligibility

Inclusion criteria

PWHB were included in the study if they were (1) 18 years or older and (2) had tested Hepatitis B surface antigen (HBsAg) positive at least 6 months prior to recruitment. The inclusion criterion for HCPs was (1) having cared for patients with Hepatitis B in a healthcare setting.

Exclusion criteria

PWHB who were in the terminal stage of Hepatitis B and had insufficient energy to participate in an interview were excluded. Only one person in the terminal stage was seen in the tertiary hospital. He was not included because he was in a state of dyspnoea (breathlessness). Also, HCPs who had less than 3 months working experience in a department where services are provided for PWHB were excluded as these HCPs might not have enough experience to discuss their perspectives on Hepatitis B in their role as HCP.

Sampling method and data collection procedure

A purposeful sampling technique was employed.^{50 51} First, posters with details of the study, including information about the purpose of the study, assurance of the voluntary nature of the study as well as the procedure for registration, were advertised in the selected health facilities. In addition, PWHB and HCPs were recruited directly through nurses at the health facilities. Among PWHB, six were recruited through the advertisement and the remaining 12 were recruited through nurses in the hospitals. Among HCPs, 10 were recruited through advertisement and 37 were recruited through nurses in the hospitals. In total, 16 participants were recruited through the advertisements and 49 through nurses. Two PWHB refused to participate. One cited time constraints as the reason and the other declined to provide a reason. An additional five HCPs did not honour the invitation as a result of an emergency call at work or a conflicting schedule with other unplanned (social) events. PWHB participated in semistructured in-depth interviews. HCPs were either interviewed or participated in a focus group discussion (FGD). The combination of interviews and FGDs for HCP assisted in understanding and describing the phenomenon comprehensively and further ensured the trustworthiness of the findings.⁵² In fact, the use of the FGDs for the HCPs stimulated each other's thoughts. However, given the sensitive nature of the topic and the extent to which responses to the study questions could be quite personal for PWHB, PWHBs were not recruited for FGDs. Interviews were deemed more appropriate.⁵³

The interviews and FGDs were conducted by the first author (CAA) who is a PhD candidate with a background in qualitative research including conducting and analysing interviews and FGDs. He is also fluent in English and the

local Ghanaian language (Twi) but all interviews and FGDs were done in English. Two days before the interviews/FGDs, participants were contacted by telephone to remind them of the appointment. The interviews/FGDs were conducted mostly in the homes of participants with chronic Hepatitis B (under trees) and the workplace of HCPs (nurses' stations and physician's consulting rooms). The informed consent form was signed by all participants following an explanation of the purpose of the study and explicit mention of the confidential and voluntary nature of their participation. In addition, permission was sought from participants to record the interviews/FGDs. Field notes were taken during the interviews and the FGDs.

Data were collected between February and November 2017. In total, 18 in-depth interviews were conducted with PWHB and 15 in-depth interviews with HCPs. Additionally, four FGDs with a composition of eight HCPs in each group were conducted. The interviews involving PWHB and HCPs lasted between 45 min and 1 hour, whereas the FGDs with HCPs lasted approximately 1 hour and 15 min. Data saturation was reached after the interviews of the 14th PWHB and 12th HCP.⁵²

Research instrument

The interviews and FGDs were guided by a semistructured protocol with the flexibility to probe. The protocol was developed based on empirical literature on Hepatitis B stigma⁵⁴ and then reviewed by an expert in stigma (SS). Subsequently, the interview protocol was piloted with two PWHB and two HCPs. Topics explored during the interviews with PWHB included: (1) participants' experiences with being treated differently because of their HBV seropositivity and the settings in which those experiences took place; (2) perceived reasons for being treated differently and (3) the impact of those experiences. Topics explored in the interviews and FGDs with HCPs were: (1) perceptions about Hepatitis B; (2) the extent to which they have provided care to someone with Hepatitis B; (3) their reactions to PWHB and (4) possible reasons for possible negative reactions to PWHB. A detailed interview protocol can be found in the online supplementary material 1.

Data analysis

Data were processed with QSR Nvivo V.10.0 and analysed using inductive thematic analysis.⁵⁵ The first author (CAA) played and listened to the audio recordings and transcribed verbatim. The first transcribed data were coded by two of the authors (CAA and SS) followed by discussions on the individual codes and, later, the categories and themes generated. Consensus was reached on the codes, and the main themes and subthemes were documented. Preliminary findings were checked with two representatives of the study population to ascertain if the findings were in line with their views and experiences. Two main themes and eight subthemes emerged from the data. These are summarised in table 1.

Table 1 Summary of themes and subthemes

Themes	Subthemes
Beliefs about Hepatitis B	Hepatitis B as highly contagious
	Hepatitis B as very severe
	Hepatitis B as a curse
Manifestations of HBV stigma	Avoidance
	Social isolation
	Excessive cautiousness by HCPs
	Procedure postponement or avoidance and task-shifting
	Breaches of confidentiality

Patient/Public involvement

Patients and the public were not involved in the development of the research questions, the design, recruitment and the conduct of the study. The study results will be shared with the participants and other relevant

stakeholders through various social media handles and conferences.

RESULTS

Demographic characteristics

We recruited, in total, 18 PWHB and 47 HCPs, of which 8 were physicians, 34 were nurses and 5 were midwives. PWHB were between 21 and 57 years of age and the HCPs were between 23 and 49 years of age. PWHB had lived with HBV between 1 and 7 years and had been diagnosed through one of the following means: self-initiated, physician initiated, during outreach screening services and as a result of hospital protocol for pregnant women. The HCPs had practised medicine, nursing or midwifery between 1 and 20 years. Detailed sociodemographic data for PWHB and HCPs are presented in [table 2](#) and [table 3](#), respectively.

Beliefs about Hepatitis B

PWHB and HCP reported that, in Ghana, Hepatitis B is considered highly contagious and very severe.

Table 2 Sociodemographic data of participants with chronic Hepatitis B

Participant number	Occupation	Year of diagnosis	Means of diagnosis
PWHB 1	Nursing	2014	Self-initiated
PWHB 2	Teacher	2011	Hospital protocol for pregnant women
PWHB 3	Caterer	2013	Hospital protocol for pregnant women
PWHB 4	Student	2016	Physician initiated
PWHB 5	Sales Manager	2016	Hospital protocol for pregnant women
PWHB 6	Trader	2012	Hospital protocol for pregnant women
PWHB 7	Unemployed	2015	Self-initiated
PWHB 8	Trader	2012	Outreach screening programme
PWHB 9	Unemployed	2016	Outreach screening programme
PWHB 10	Banker	2008	Outreach screening programme
PWHB 11	Unemployed	2010	Outreach screening programme
PWHB 12	Teacher	2015	Self-initiated
PWHB 13	Unemployed	2011	Hospital protocol for pregnant women
PWHB 14	Housewife	2014	Outreach screening programme
PWHB 15	Trader	2009	Self-initiated
PWHB 16	Teacher	2010	Self-initiated
PWHB 17	Trader	2013	Hospital protocol for pregnant women
PWHB 18	Accountant	2015	Self-initiated

Table 3 Sociodemographic data of healthcare providers

Pseudonyms	Occupation	Years of practice	Pseudonyms	Occupation	Years of practice
HCP 1	Physician	4	FGD 1	Nurse	10
HCP 2	Nurse	7	FGD 2	Nurse	3
HCP 3	Nurse	9	FGD 3	Nurse	5
HCP 4	Physicians	3	FGD 4	Nurse	9
HCP 5	Nurse	2	FGD 5	Nurse	11
HCP 6	Nurse	4	FGD 6	Nurse	3
HCP 7	Physicians	5	FGD 7	Nurse	4
HCP 8	Nurse	5	FGD 8	Nurse	20
HCP 9	Physician	3	FGD 9	Nurse	9
HCP 10	Nurse	9	FGD 10	Nurse	3
HCP 11	Nurse	3	FGD 11	Nurse	11
HCP 12	Physician	14	FGD 12	Nurse	6
HCP 13	Physician	4	FGD 13	Midwife	8
HCP 14	Physician	4	FGD 14	Nurse	4
HCP 15	Physician	9	FGD 15	Midwife	9
			FGD 16	Nurse	4
			FGD 17	Nurse	7
			FGD 18	Nurse	2
			FGD 19	Nurse	7
			FGD 20	Nurse	4
			FGD 21	Nurse	2
			FGD 22	Midwife	7
			FGD 23	Nurse	8
			FGD 24	Nurse	20
			FGD 25	Nurse	5
			FGD 26	Nurse	3
			FGD 27	Midwife	11
			FGD 28	Nurse	8
			FGD 29	Nurse	1
			FGD 30	Midwife	14
			FGD 31	Nurse	4
			FGD 32	Nurse	3

Additionally, Hepatitis B is sometimes associated with curses. These themes are described in detail below.

Hepatitis B as highly contagious

Participants with Hepatitis B reported that people in their community believe that Hepatitis B can be acquired through casual contact such as handshaking, touching and eating from the same bowl with someone with Hepatitis B. These perceived modes of transmission were reported to have created fear and panic within the Ghanaian social arena. The situation was further posited to be compounded by the belief that sweat is a medium by which Hepatitis B can be transmitted. One participant with chronic Hepatitis B said the following:

It is well known that when someone with Hepatitis B's sweat touches you, you can also get the disease or when he shares the same eating bowl with you, you can be infected with the virus by his saliva. This information scares many people and therefore as soon as they get to know you have Hepatitis B, they tend to dissociate themselves from you. (PWHB, South-IDI 2 (All names have been changed to protect the identity of participants))

Another participant with chronic Hepatitis B also recounted his experience in school as follows:

When we were in school, we knew that the virus could be found in human sweat. With this understanding,

when someone meets you lying on his mattress, he becomes very furious because you have the tendency of infecting him with the virus. If you use someone's spoon or cup and he sees it, that is it, you will have it forever. He will prefer to buy a new one than to use the one used by you to get the virus. (PWHB, North-IDI 7)

According to one PWHB, the fear of infection on the part of others is the result of a lack of knowledge,

There is a lot of false information about Hepatitis B in the public domain which puts fear in everyone. Some have the mind-set that you can get the virus from an infected person through a handshake. This makes people alarmed when they know you have the virus. (PWHB, South-IDI 11)

The belief that Hepatitis B is easily transmitted was also held by HCPs. Some reported that because of this, they have assigned unique names to chronic Hepatitis B positive patients for easy identification and notification. Also, HCPs reported treating PWHB differently because they fear possible infection.

I am a midwife and in the ward, we have given those with Hepatitis B names. We call them candidates. When we identify you as a candidate, most midwives don't want to touch such a person. Even we ignore their money because we believe that where she kept the money sweat could get to it and therefore we don't like it. (HCP, North-FGD 13)

Hepatitis B as very severe

Participants indicated that many people think Hepatitis B is easily transmitted and is very severe. Hepatitis B was claimed to be a condition with poor prognosis that eventually leads to death. One participant with chronic Hepatitis B shared her view as follows:

Everyone is afraid of the Hepatitis B virus. Since it is known that it kills, no one wants to have anything to do with people who have it. Many people are aware of HIV but because it is well publicised that Hepatitis B is more deadly than HIV, people are terrified when getting closer to those who are known to have Hepatitis B. (PWHB, South-IDI 18).

Another HCP said, People who are aware of Hepatitis B know that it kills. They are very cautious when they hear that someone has Hepatitis B. (HCP, South-IDI 2).

Along similar lines, participants reported Hepatitis B to be incurable.

What scares us is the information that Hepatitis B has no cure. It therefore means that is either you die with it or you live with it forever. HIV which is a popular disease seems to be better than Hepatitis B because there are drugs to keep you alive when you get it. (PWHB, North-IDI 14)

The severity of Hepatitis B was further emphasised by comparisons that were made with HIV, a condition that is also considered to be very severe. Interestingly, Hepatitis B was considered to be more severe than HIV:

People say it is deadly, it kills faster than HIV/AIDS. (HCP, South-IDI 12)

Hepatitis B as a curse

Another belief held about Hepatitis B by participants is that Hepatitis B affects people who have been cursed for some kind of wrong doing. This was reported to be based on the fact that people in advanced stages of Hepatitis B clinically present with ascites, jaundice and oedema, and these presentations are linked to punishment from gods in Ghanaian society. According to a number of the participants, people in their community believe that people with swollen abdomens and feet are cursed for not respecting or taking care of their parents.

Ascites [enlarged abdomen] and oedema [swollen feet] is one thing that society perceives as caused by curses. Once they see it, they believe that the person has been cursed. The family members don't want to get closer since they feel that it is happening because of the person's bad deeds. (HCP, North-FGD 16)

Participants spoke of how, in certain circumstances, family members seek alternative treatment for Hepatitis B when they are convinced that the gods are the cause of the complications. They seek spiritual support and this often delays healthcare seeking. One HCP recounted her experience with her father who had been Hepatitis B positive.

My father had Hepatitis B and died. He grew very lean, his stomach bloated and they said it was a curse from the family. He wasn't taken to the hospital and he was neglected by his siblings. He was moved from one prayer camp to the other, one church to the other, thinking he would be cured but when he was brought back to the house, the infection was worse than before. His eyes were very yellowish and he was very lean. (HCP, South-IDI 11)

Furthermore, a report by a HCP revealed some of the rituals that are performed in the healthcare settings before the corpse of a person with chronic Hepatitis B is taken out for a burial. According to the participant, this is done to prevent possible transmission of the disease to the family members of the deceased.

Sometimes when they [PWHB] die, the relatives perform some rituals to cleanse themselves before the body is conveyed to the morgue. (HCP, North-IDI 6)

Manifestations of stigma

In addition to reporting common beliefs about Hepatitis B in Ghana, participants also reported a number of ways

in which Hepatitis B stigma manifests, in general and specifically in healthcare settings.

Avoidance

One manifestation of Hepatitis B stigma reported by participants was avoidance. A participant with chronic Hepatitis B recounted her experience following diagnosis and disclosure of her status to her close relative.

As soon as they see that you have Hepatitis B, they start avoiding you; something you pick, they won't pick; something you have used, they don't want to get closer to it. At first, I used to do things together with my uncle. Whenever he is eating, I can put my hand in it and eat with him. After I told him that I was Hepatitis B positive, he avoids me completely. Anytime he returns from work he just greets me and enters his room. I don't see him to chat and joke like the way we used to. (PWHB, South-IDI 3)

Another participant with chronic Hepatitis B also, reported avoidance by family as follows:

When my household members see me, they change their conversation. When they are chatting and I go to sit down, then they get up. They treat you as if you have shit on yourself. Everyone leaves you with so many excuses. (PWHB, North-IDI 16)

Yet another participant with Hepatitis B reported the following:

Many people see those with Hepatitis B as sources of infection because they think it can be transmitted through sweat. They are sometimes afraid to go closer to them especially when the person looks jaundiced (yellowish) and the stomach becomes big. Everyone becomes scared and they may treat the person like a leper by distancing themselves from the person. (PWHB, South-IDI 15)

Avoidance was also reported to occur in the healthcare settings. One HCP shared how she avoided a colleague after learning she had Hepatitis B.

I was working at one sub-district and the staff were friendly and so we were eating together. One day, we were chatting and a colleague said, 'she is Hepatitis B positive'. From that day, I never ate with them again because I felt uncomfortable. Knowing that the virus can be in the saliva and there could be exchange of saliva while eating from the same bowl, I was afraid of getting the infection so I stopped eating with them. (HCP, North-FGD 8)

Some of the avoidance reported was said to be based on speculations. People who were known or suspected to have a sexual relationship with a person with Hepatitis B were also avoided.

I was in a community health centre with subordinates who were young nurses. They were eating together,

doing everything together and very close until there was a death of a man. It came out that the person died of Hepatitis B and one of the nurses was said to be the girlfriend. After the funeral, the girl was deserted. The eating together could not continue and, in fact, the girl became very worried and miserable because the relationship with her colleagues changed. (HCP, North-FGD 30)

Another participant narrated a similar experience as follows:

I stayed in a compound house with a certain lady who was befriending someone positive of Hepatitis B. Later, somebody in the yard got to know that the man was Hepatitis B positive and the news spread in the yard. Nobody was coming near her veranda because they concluded that once the guy had Hepatitis B then the lady has also gotten it. When they are sitting in the yard and she comes to sit, they all enter their rooms. Nobody was going close to her until she had a quarrel with one of the residents and she was insulted as having Hepatitis B. That was when the lady got to know why everybody was avoiding her. (HCP, North-FGD 4)

Additionally, participants indicated that family members sometimes distance themselves because they see distancing themselves as a way of escaping the wrath of the gods, reflecting again the belief that Hepatitis B can be the result of a curse from the gods.

People fear to be closer to someone who has been cursed so they withdraw from the person in order not to attract the anger of the gods. (HCP, North-FGD 27)

Social isolation

Participants also reported social isolation as a manifestation of stigma. They reported that, in some senior high schools where students reside in the dormitories, those with chronic Hepatitis B are isolated from their peers in an effort to prevent possible transmission of the virus to other students. One HCP narrated an encounter she had with a man, whose son suffered this treatment in school, as follows:

I met one man who was lamenting that his son in a senior high school was ejected from the school dormitory because he tested Hepatitis B positive. The boy has been isolated and now sleeps in the classroom. The school authorities feel that, if they don't isolate those who are positive, they will end up infecting everybody and more students. Parents are compelled to get houses outside school campus for such students. (HCP, North-FGD 14)

Participants also indicated that, in some parts of Northern Ghana, people who test Hepatitis B positive are subsequently confined to their rooms. They are treated

as outcasts and have many social restrictions. Additionally, some PWHB reported having family roles taken from them and being denied participation in family functions. A participant with chronic Hepatitis B shared her observations as follows:

The person is isolated when family members are made aware of his/her Hepatitis B positive status. If they were cooking in one pot, the person ceases to cook with them. They give them their own room and sometimes put the person very far away. They [PWHB] don't move around and always stay inside mourning their dead when not dead. They only come and throw their food to them to take and eat. They won't let you feel that you are also normal like them. (PWHB, North-DI 8)

Similarly, a HCP recounted her experience with a family that nearly ex-communicated their daughter because of fear of possible transmission of the virus to other relations.

I had a fourteen-year-old pregnant lady who had Hepatitis B. I counselled her and the mother. When they returned to the house, the father denied the girl opportunity to stay with them to prevent others getting infected. The father thought that people with Hepatitis B are not supposed to eat with anyone and the person must use a separate bowl, cups etc. Based on this, he could not accept the girl in the house for fear of passing on the infection to the entire family. (HCP, North-FGD 21)

The social isolation of PWHB was additionally reported to occur in healthcare settings. In this context, social isolation occurred because, according to participants, people tend to believe, as reported above, that an infected person can pass the infection to others through sweat. This was claimed to motivate HCPs actions to separate PWHB from other patients.

We put them [PWHB] at the extreme corner where no one goes there. (HCP, North-IDI 3)

Isolation of PWHB was also reported to worsen when PWHB exhibit severe forms of jaundice.

Some people feel that when you have Hepatitis B and you look yellowish, it means that the viruses are too many in your blood. At that point, everyone withdraws. When the person dies, they don't waste time to keep his/her body for proper funeral but quickly bury the person. I have seen a number of cases like that in my village. (PWHB, North-IDI 3)

Stigmatisation in healthcare settings

Specific manifestations of stigma in healthcare settings were reported as well. In healthcare settings, stigma was reported to manifest as avoidance and social isolation as outlined above and as excessive cautiousness, task-shifting,

procedure postponement and avoidance and breaches of confidentiality.

Excessive cautiousness

Participants reported that excessive cautiousness was taken by HCPs when providing care to patients with chronic Hepatitis B. This was evidenced by the use of extreme infection prevention precautions. In some instances, HCPs stated that they wore extra gloves to prevent possible acquisition of the virus.

Anytime I am managing someone with Hepatitis B, I am extra careful. I put on more than one glove and also wash my hands regularly. (HCP, South-FGD 20)

Another HCP explained how this is related to the belief that Hepatitis B is highly contagious.

When you get to know that the patient has Hepatitis B infection, the mind-set changes outright. You become very cautious because you are afraid of getting infected. (HCP, South-IDI 9)

Notwithstanding, some HCPs indicated that their actions were dependent on the kind of procedure.

Sometimes it depends on what you are going to do for the person. For instance, when I am going to empty the urine bag, I put on three gloves. But when I am feeding them, I don't do that because I know I am not coming into contact with anybody's fluid. (HCP, South-FGD 22)

Some HCPs reported that negative perceptions about Hepatitis B compromise, to some extent, the quality of care individuals with chronic Hepatitis B receive.

I've seen a couple of cases where midwives were very careful not wanting to assist the delivery of Hepatitis B positive woman. Even the baby that was born, they were very sceptical touching her and the mother. The way they handled them and the way they talked about it—'whispering' when they are handing over—sometimes it is very obvious that they are stigmatising the client.' (HCP, South- IDI 1)

Procedure postponement or avoidance and task-shifting

The majority of the participating HCPs indicated that postponement or avoidance of procedures and task shifting are common when caring for PWHB. This was reported to occur because of the perceived contagiousness of Hepatitis B.

When we see them [PWHB] at the critical stage, some vomiting blood and coughing out blood, you will see some nurses postponing procedures because they think that they can be infected. (HCP, North-FGD 5)

Another participant reported procedure avoidance:

I ever sent a patient to the hospital. The intravenous line infiltrated and the nurses were supposed to change it. I was amazed that no nurse was ready to

do it. This nurse will say to the other to go and do it. Another said let's wait for the doctor and giggled. So I was getting afraid. Is this person having HIV or what that no one seems interested working on him? (HCP, North- FGD 23)

Yet another HCP narrated a similar experience with a Hepatitis B positive patient as follows:

We had one Hepatitis B case that came in a coma state and if you look at the severity of the condition, most of the staff were not willing to provide any service for the patient. The patient was restless and ended up losing his life after 3 days. After he died, nobody even wanted to go closer to his dead body because we were afraid that we could be infected. (HCP, South-IDI 10)

A number of the participants indicated that, when a patient has Hepatitis B, some HCPs shift their tasks such that student nurses have to perform them. A nurse recounted her experience during her formal clinical training as follows:

During our clinical placement, when cases like Hepatitis B are admitted, it was we, the students, that the nurses used to send to go and manage those clients. In fact, they won't let you know the exact condition until you cannot do something. Even that, when one of them is coming to help you, the gloves will be more than five. Even with that, she will still come and stand and say, 'hold this place', 'do that'. She will not do it. So, if they begin to do that and you also take the patient's folder and you see that it is Hepatitis B, then you advise yourself (HCP, North-FGD 19)

Similarly, another nurse reported the following experience:

During my first clinical attachment as a student nurse, Hepatitis B patients were put in the cubicle or an isolated veranda. Anytime they [nurses] were to attend to them, either during dressing, checking of vital signs, it was student nurses that they ask us to go and do. (HCP, North-FGD 10)

Breaches of confidentiality

The final manifestation of stigma reported to occur in healthcare settings was breaches of confidentiality. Participants reported that some HCPs fail to maintain confidentiality. According to participants working in the healthcare sector, it is common to receive information about PWHB from a colleague in the various hospital wards and units.

The moment they diagnose somebody Hepatitis B positive, even if it is one single nurse who is on duty, the whole hospital will hear. The nurse will circulate the information until that ward nurses finish and everybody is informed. If the person is pregnant, it will even spread to the antenatal unit and then to

maternity ward and every nurse become careful with such a person. (HCP, North-FGD 28)

DISCUSSION

This study set out to explore beliefs contributing to Hepatitis B stigma, and the ways in which Hepatitis B stigma manifests, from the perspectives of PWHB as well as healthcare providers in Northern and Southern Ghana. Our findings demonstrated that three main beliefs underlie Hepatitis B stigma in Ghana, namely (1) the belief that Hepatitis B is highly contagious; (2) the belief that Hepatitis B is very severe and (c) the belief that Hepatitis B is caused by curses. In healthcare settings, stigmatisation manifested as excessive cautiousness, procedure postponement or avoidance, task-shifting and breaches of confidentiality.

The belief that Hepatitis B is highly contagious was reported by both PWHB and HCPs as central to stigma in Ghana. Contributing to this perceived contagiousness were beliefs that Hepatitis B can be transmitted through casual contact such as handshaking, touching and the sharing of eating utensils with PWHB and a focus on body fluids, such as sweat, as a source of infection. Stigmatisation originating from a fear of infection is not particular to Ghana, but has been reported in other locations as well.^{26 33 42 56–59} For example, in Pakistan, Rafique and colleagues³³ indicated that PWHB experienced stigmatising reactions from their families who feared infection and thus refused to share eating and drinking utensils, as well as soap and towels, with relatives living with chronic Hepatitis B. That sweat was considered to be an important source of HBV transmission leading to avoidance of PWHB has also previously been documented by a study conducted in Nigeria.⁶⁰ However, sweat is not a vehicle for HBV transmission⁶¹ and this suggests a knowledge deficit regarding Hepatitis B transmission among the general public in Ghana and among HCPs. This is particularly disconcerting given that HCPs are considered an important source of Hepatitis B information by their patients.⁶²

Our study further showed that the belief that Hepatitis B is very severe is also present in Ghana and that this belief contributes to stigmatisation. Generally, participants perceived Hepatitis B as deadly and reported that others think PWHB will inevitably die. The belief that Hepatitis B is very severe is consistent with a study conducted by Upadhyaya *et al*⁶³ in the USA, where the role and attitudes of primary care physicians in Hepatitis B diagnosis and treatment were assessed. The results showed that physicians perceived Hepatitis B as very serious.⁶³ Interestingly, in our study, and in previous studies conducted in Ghana³⁴ and in the Netherlands,⁶⁴ Hepatitis B was associated with, and perceived to be even more severe, than HIV. It is possible that in the Ghanaian context, this is attributable to the fact that Hepatitis B is not optimally managed. Unlike HIV, antiretroviral treatment for

Hepatitis B is not readily available and affordable.^{16 44} Additionally, the number of specialised clinics that can monitor and support PWHB is inadequate³⁴ and the WHO policy on treatment, management and support of PWHB in Ghana has not yet been implemented.^{34 65} Further, with the exception of Hepatitis B testing, which is covered by the national health insurance scheme when requested by physicians, Hepatitis B vaccination is offered at a fee in Ghana. The only national policy on Hepatitis B prevention in Ghana is the administration of Hepatitis B pentavalent vaccine to newborn babies at 6, 10 and 14 weeks after birth.³⁴

Another finding of this study was that, in Ghana, there is a belief that Hepatitis B is caused by curses. An earlier study showed that people do attach superstitious beliefs to Hepatitis B in Ghana.³⁴ Also, a study conducted by Adjei *et al.*⁶⁶ found that 86% (n=168) of participants linked the cause of Hepatitis B to curses. This association is unsurprising given that some clinical manifestations of Hepatitis B, including swollen abdomen and feet, are analogous to the perceived outcomes of a curse in Ghanaian culture. In Ghana, people are particularly cautious about handling items perceived to be cursed as not handling them can help to avoid possible transfer of the consequences of that curse.

In addition to documenting beliefs about Hepatitis B that contribute to stigmatisation, we also explored the manifestations of Hepatitis B stigma in Ghana. One manifestation was avoidance. This is consistent with other studies.^{56 57} For example, in a study conducted in Japan with a sample of the working population, Eguchi and Wada⁵⁶ found that 32.1% of their study participants avoided physical contact with colleagues after learning their HBV positive status. Similarly, in an Iranian study, patients with Hepatitis B reported believing that saliva is a source of Hepatitis B infection and therefore avoiding bodily contact with close relations including kissing.⁵⁹

In our study, we also found that stigma manifests as social isolation. Our finding that students were isolated from other students in school dormitories because of their Hepatitis B status is similar to a finding from a study in China where a university student with Hepatitis B was put in a single room instead of a shared dormitory.⁵⁸ In a study by Yang and Wu⁶⁷ the findings showed that some universities and kindergartens in China refused to admit prospective students who were Hepatitis B positive.

Our study also looked specifically at Hepatitis B stigma in healthcare settings. We ascertained that stigmatisation took form as excessive cautiousness, procedure postponement or avoidance, task-shifting and breaches of confidentiality. Perhaps inadequate knowledge and fear of acquisition of HBV among the HCPs led to the excessive cautiousness and fear. Currently, there is no Hepatitis B vaccination policy in place for HCPs in Ghana. HCPs, therefore, freely choose to vaccinate against the HBV based on their willingness and financial means to do so because the vaccination is not free. Our finding that HCP uses excessive precautions due to fear of acquisition of

HBV by the HCPs found in this study has been previously documented by Yu and colleagues⁶⁸ in China. Similarly, Wada *et al.*,³⁸ in their study conducted in Japan, reported that some nurses were also reluctant to care for PWHB due to a perceived risk of infection. In another study conducted in Iran with chronic Hepatitis B patients by Dehkordi and others,³⁹ nurses and doctors were reported to be hesitant caring for PWHB after realising they have Hepatitis B.

Our findings have important practical implications. First, the findings provide important insight on how to go about reducing Hepatitis B stigma. Given the prevalence of incorrect knowledge, as reflected in the beliefs about Hepatitis B, we recommend public awareness campaigns that emphasise Hepatitis B transmission routes. Also, given the manifestations of the stigma in the healthcare settings, we feel that a continuing professional development programme for HCP on Hepatitis B is called for as this can enhance HCPs knowledge in parallel to public awareness campaigns. Additionally, we recommend the development and implementation of policy on HBV vaccination for HCPs that makes this free to HCP, as this may increase HCPs confidence when caring for PWHB. In developing public awareness campaigns and professional development programme, we consider it important to do this based on both theory and evidence and in collaboration with target populations, as this improves the likelihood that these interventions will effectively reduce Hepatitis B stigma in Ghana.⁶⁹ In addition, we recommend providing PWHB with counselling where they can learn to use effective coping strategies when confronted with stigma. Such coping strategies include seeking social support, affiliating with others with Hepatitis B, religious coping and positive reappraisal. These coping strategies have been shown to build resilience against the negative effects of stigmatisation.^{19 70} Additionally, it may be beneficial to explore the possible use or adaptation of existing effective stigma reduction interventions for PWHB such as psycho-educational interventions that focus on education, skill building, empowerment and social support.⁷¹

The findings of this study should be viewed in light of a few limitations. Although this study provided insights into the beliefs contributing to Hepatitis B stigma and the manifestations of stigma in Ghana, it did not establish the extent to which these beliefs are endorsed or how often manifestations of stigma occur. We, therefore, recommend investigating belief endorsement and the prevalence of stigma manifestations quantitatively in a large representative sample of the Ghanaian population. Second, given that PWHB participants had lived with the infection for a period between 1 and 7 years and were asked to recall their experiences retrospectively, there was potential for recall bias. We, however, sought to reduce this by asking follow-up questions to confirm or verify participants' experiences. The third possible limitation of this study was the exclusion of PWHB who were in the terminal stage of the disease. We recognise that their experiences with stigma might differ from our study

participants. One important strength of this study is the use of FGDs that allowed the participant's to build on the ideas of their colleagues which added some details to the data.

CONCLUSION

This study has provided insights about beliefs contributing to Hepatitis B stigma in Ghana and the manifestations of Hepatitis B stigma, both generally and specifically in healthcare settings. We found that beliefs that Hepatitis B is highly contagious, very severe and caused by a curse are present and contribute to the stigmatisation of PWHB in Ghana. Hepatitis B stigmatisation manifested as avoidance and social isolation. In the healthcare settings, stigma manifested as excessive cautiousness, procedure postponement or avoidance, task-shifting and breaches of confidentiality. We recommend interventions that seek to alter the beliefs contributing to Hepatitis B stigma in Ghana, starting with efforts that correct knowledge deficits.

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