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The challenge of stigma among people with hepatitis B in Ghana: a qualitative study

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ABSTRACT

Objective: This study explored the perspectives of people with hepatitis B and healthcare providers on the beliefs contributing to hepatitis B stigma in Northern and Southern Ghana and the ways in which hepatitis B stigma manifests.

Design: The study 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 version 10.0 and analysed using content analysis.

Settings: Participants were recruited from one tertiary and one regional hospital in Ghana.

Participants: Overall, 18 people with hepatitis B and 47 healthcare providers (physicians, nurses, and midwives) between the ages of 21 and 57 years participated in the study.

Results: The findings of the study showed that people with hepatitis B are faced with stigma in their socio-cultural 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, isolation, and physical distance. Also, in healthcare

settings, excessive cautiousness, task-shifting, procedure avoidance, breaches of confidentiality, and silence by healthcare providers were reported.

Conclusions: Implementation of programmes that increase public awarenenes about hepatitis B transmission are needed in the study settings. Capacity training of healthcare providers on epidemiology of hepatitis B is very crucial. Also, effective theory and evidence-based stigma reduction interventions are recommended.

Key words: Stigma, challenge, hepatitis B, infection, Ghana.

Strengths and limitations of this study

- This study is the first to document hepatitis B stigma in Ghana. The outcome of this study paves the way for future studies to measure quantitatively the extent of hepatitis B stigma in the study context.
- Triangulation of the data across people with hepatitis B and different categories of healthcare providers (physicians, nurses, and midwives) added richness to the findings. Also, the verbatim presentation of participants' views is a strength of this study.
- The findings are limited by the small sample size and therefore one must be cautious in generalising these findings to the entire population.
- We recognise the possibility of recall bias. However, this was reduced to some extent, by asking follow-up questions to confirm participant's experiences.

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 (i.e. hepatocellular carcinoma and cirrhosis) were recorded in 2015.[2] Sub-Saharan Africa is disproportionately affected [2] 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 7-12] 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, and intimate 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, diseases with some risk of transmission are associated with stigma.[17 18] This is well reported for conditions such as tuberculosis, HIV, and mental illnesses.[19-22] Similarly, people with hepatitis B (PWHB) are likely to be stigmatised.[23-29] Stigmatisation is a socially and culturally constituted process whereby a person is first labelled as different and then devalued, leading to status loss and discrimination.[30 31] Link and Phelan[31] 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). Because hepatitis B is an infectious disease, disease avoidance as a motivation for stigmatisation is likely. This is supported by evidence from Canada and Pakistan showing that PWHB experience diverse degrees of stigma because of the perceived infectiousness of HBV.[32-33] Stigmatisation may also 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] Alongside, there is data showing ignorance about HBV routes of transmission and how that ignorance contributes to hepatitis B stigma.[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 health care settings.[38 39] For example, Wada and colleagues[38] found that some healthcare providers in Japan were reluctant to care for clients with hepatitis B due to fear of infection.

The stigmatisation of PWHB has many consequences. It has been found to create an environment of secrecy and denial, can lead to depression, and can be a barrier to health care 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 one's HBV status can be a barrier to preventing transmission to others.[44] Further, stigmatisation can serve to deter people at risk for HBV infection from being 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 the perspectives of PWHB and HCPs on the beliefs contributing to hepatitis B stigma in Northern and Southern Ghana and the ways in which hepatitis B stigma manifests. Understanding this phenomenon is important as it can inform the design of effective hepatitis B and stigma prevention interventions and 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] Ethical approval was given by the Korle-Bu Institutional Review Board (IRB).

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 ten 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 clients with liver conditions, including hepatitis B, are run at the tertiary hospitals whereas PWHB are mostly treated as out-patient cases in regional hospitals. One tertiary hospital in the south and one regional hospital in the North were selected for the study.

Study Population

We recruited PWHB and HCPs including 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.

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 for at least 6 months. The inclusion criterion for HCPs was (1) having cared for hepatitis B clients in a healthcare setting.

Exclusion Criteria

PWHB who were in the terminal stage of the disease and had less energy to go through the interview session were excluded. Also, HCPs who had less than three months working experience in a department where services are provided for PWHB were excluded as these HCPs might not have enough experience with hepatitis B.

Sampling Method and Data Collection Procedure

A purposeful homogenous sampling technique was employed.[50 51] First, posters with details of the study, including 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. PWHB and HCPs were also recruited directly through nurses at the health facilities. Overall, 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. Another 5 HCPs did not honour the invitation as a result of an emergency call at work or conflicting schedule with other unplanned social events. PWHB participated in semi-structured in-depth interviews. HCPs were either interviewed or participated in a focus group discussion (FGD). Given the sensitive nature of the topic and the extent to which responses to the study questions could be quite personal for PWHB, PWHB were not recruited for FGDs. Interviews were deemed more appropriate.[52] Two days before the interview/FGD, participants were contacted by telephone to remind them of the appointment. The interviews/FGDs were conducted mostly in the homes of those with

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 interview/FGD. 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, 4 FGD with a composition of 8 HCPs in each group were conducted. The interviews involving PWHB and HCPs lasted between 45 minutes and 1 hour whereas the FGDs with HCPs lasted approximately 1 hour and 15 minutes. Data saturation was reached after the interview of the 14th PWHB and 12th HCP.[53]

Research Instrument

The interview and FGD were guided by a semi-structured protocol with the flexibility to probe. The protocol was developed based on empirical literature on hepatitis B stigma and then reviewed by an expert in stigma (SS). Subsequently, the interview protocol was piloted with two PWHB and two HCPs. The interviews and FGD were conducted by the first author (CAA) who is fluent in English and the local Ghanaian language (Twi) but all interviews and FGD were done in English. Topics explored during the interviews with PWHB include (1) participants experiences being treated poorly or differently because of their HBV sero-positivity and the settings in which those experiences took place (2) perceived reasons for being treated poorly or differently (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 and, their reactions (3) possible reasons for negative reactions to PWHB. A detailed interview protocol can be found in the supplementary material 1.

Data Analysis

Data were processed with QSR Nvivo version 10.0 and analysed using content analysis.[54] 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, categories, and themes generated. At the end, a consensus was reached on the codes, and the main themes and sub-themes were documented. Two main themes and eight sub-themes emerged from the data. These are described in the sections below.

Patient/Public Involvement

Patients and the public were not involved in the development of the research questions, the design, recruitment, and conduct of the study. The study results will be shared with the participants and other relevant stakeholders through various social media handles, and conference presentations.

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 the infection 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 socio-demographic data for PWHB and HCPs are presented in table 1 and table 2 respectively.

Beliefs About Hepatitis B

PWHB and HCP reported that, in Ghana, hepatitis B is considered highly contagious and very severe. Additionally, it is sometimes associated with curses. These themes are described in detail below.

Hepatitis B as highly contagious

It was widely reported by participants with hepatitis B 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 an infected person. These 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 hepatitis B said,

"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 - IDI 2 [1])

Another participant with hepatitis B also recounted his experience in school,

"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 - IDI 7)

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

[1] All names have been changed to protect the identity of participants

"There is a lot of false information about hepatitis B in the public domain which put 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 - IDI 11)

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 - FGD 21)

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 hepatitis B positive clients for easy identification and notification. Also, HCPs reported treating PWHB differently because they fear possible infection. Some of the reactions from HCP are as follows,

"I am a midwife and in the ward and 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 - FGD 13)

Fear of infection on the part of HCPs was also said to result in hepatitis B clients being neglected by some HCPs.

"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 three days. After he died, nobody even wanted to go closer to his dead body because we were afraid that we could be infected." (HCP - IDI 10)

Hepatitis B as very severe

Participants also indicated that many people think hepatitis B is not only easily transmittable but very severe. Hepatitis B was claimed to be seen as a condition with poor prognosis which eventually leads to death. One participant with hepatitis B shared her view,

"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 - 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 - IDI 2).

Participants emphasized the severity by comparing hepatitis B to HIV/AIDS as illustrated by this quote: "*People say it is deadly, it kills faster than HIV/AIDS."* (HCP – IDI 12)
A belief that was said to contribute to the perceived severity of hepatitis B is the belief that hepatitis B is 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 – IDI 14)

Hepatitis B as a curse
Another belief held about hepatitis B is that it affects people who have been cursed for their 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 the Ghanaian context. According to a number of the participants, people in their community believe that the swollen abdomen and feet that characterise hepatitis B suggest that those infected are cursed. This was vividly reported by some HCPs.

"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 - 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 health care 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 – IDI 11)

Furthermore, a report by an HCP revealed some of the rituals that are performed in the healthcare settings before the corpse of someone with hepatitis B is taken out for a burial. This according to the participant is done to prevent possible effect of the disease on the family members of the deceased.
She said,

"Sometimes when they [PWHB] *die, the relatives perform some rituals to cleanse themselves before the body is conveyed to the morgue."* (HCP – 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, both in general and specifically in healthcare settings.

Avoidance

Participants reported various ways in which stigmatisation was expressed toward PWHB. Avoidance was a typical reaction reported. A participant with hepatitis B recounted her experience following diagnosis and disclosure of her status to her close relation.

"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 - IDI 3)

Another participant with hepatitis B also said,

"Hmmmm! *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 – IDI 16)

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 - FGD 8)

Some of the avoidance was said to be based on speculations. People who were known or suspected to have a sexual relationship with a hepatitis B positive individual were also said to be 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 - FGD 30)

Another participant narrated a similar experience,

"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 - FGD 4)

Isolation and physical distance

Participants also reported isolation and increased physical distance as manifestations of stigma. They reported that, in some senior high schools where students reside in the dormitories, those with hepatitis B are isolated form 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,

"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 - FGD 14)

Participants also indicated that, in some parts of Northern Ghana, people who test hepatitis B positive are confined to their rooms. They are treated as outcasts and have many social restrictions. Additionally, it was reported that some PWHB have family roles taken from them and are denied participation in family functions. A hepatitis B positive participant shared her observations,

"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 – IDI 8)

The social isolation of PWHB was also reported to occur in the healthcare settings as well. In this context, isolation occurred because, according to the 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 clients. *"We put them* [PWHB] *at the extreme corner where no one goes there."* (HCP - IDI 3)

Another PWHB shared his thoughts,

"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 – IDI 15)

The public reaction toward PWHB was said to worsen when they 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 - IDI 3)

Furthermore, participants indicated that family members sometimes distance themselves because they consider it as way of escaping the wrath of the gods, reflecting again the belief that hepatitis B is 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 - FGD 27)

Stigmatisation in health care settings

Specific manifestations of stigma in health care settings were reported as well. There, stigma not only manifested as avoidance, increased physical distance, and isolation as outlined above, but also as excessive cautiousness, task-shifting, procedure avoidance, breaches of confidentiality, and silence.

Excessive cautiousness by HCPs

Participants reported that excessive cautiousness was taken by HCPs when provided care to clients with 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 gloves and also wash my hands regularly." (HCP - 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 - 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 - FGD 22)

Some HCPs reported that their negative perception about hepatitis B compromises, to some extent, their professional ethics.

"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- IDI 1)

Task-shifting and procedure avoidance

The majority of the HCPs indicated that postponement of procedures and task shifting are common when caring for PWHB. In some instances, HCPs failed to perform nursing procedures but, rather, delayed care when the client was identified as having hepatitis B. This too 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 - FGD 5)

Another participant said,

"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 - FGD 23)

A number of the participants indicated that some HCPs shift their tasks such that student nurses have to perform them. A nurse recounted her experience during her formal clinical training,

"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 - FGD 19)

Another nurse said,

"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-FGD 10)

Breaches of confidentiality and silence

Two final manifestations of stigma that were reported to occur in healthcare settings were breaches of confidentiality and, conversely, silence, thus simply not discussing hepatitis B. Participants reported that some HCPs indeed fail to maintain confidentiality. According to some participants, 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 - FGD 28)

Conversely, silence on hepatitis B was reported as well. One participant explained the kind of "silence" reactions that occurred in health care settings.

"Personally I really feel disheartened during that moment when we are operating on hepatitis B patients. The whole theatre setting becomes like a horror scene. The staff seem to be afraid of possible infection. The room becomes quiet and the basic care becomes alarmed. It's like hell has entered the theatre." (HCP - IDI 1)

DISCUSSION

This study set out to explore the perspectives of PWHB and HCPs on the beliefs contributing to hepatitis B stigma in Northern and Southern Ghana and the ways in which hepatitis B stigma manifests. Our findings show 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. Our findings also show that hepatitis B stigmatisation manifests as avoidance, isolation, and physical distance. In the healthcare setting, excessive cautiousness, task-shifting, procedure avoidance, breaches of confidentiality, and silence by HCPs were also reported.

The belief that hepatitis B is highly contagious was reported by both PWHB and HCPs as central to the existence of 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 hepatitis B infected persons 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.[26 33 42 55-59] For example, in Parkistan, Rafique and colleagues[33] indicated that PWHB suffered 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 hepatitis B. That sweat was claimed to be be an important source of HBV transmission thus leading to avoidance of PWHB has also previously been documented by a study conducted in Nigeria.[60] That sweat is in fact not a vehicle for HBV transmission[61] suggests a knowledge deficit regarding hepatitis B transmission not only among the general public in Ghana but also among HCPs. This is particularly disconcerting given that HCPs are considered an important source of hepatitis B information by their clients.[62]

Our study further showed that the belief that hepatitis B is very severe is also present in Ghana and that this contributes to stigmatisation. Generally, participants perceived hepatitis B as deadly. This is consistent with a study conducted by Upadhyaya et al.[63] in the United State. In that study Upadhyaya and colleagues assessed the role and attitude of primary care physicians in hepatitis B diagnosis and treatment. They found that physicians perceived hepatitis B as very serious.[63] Interestingly, in our study and previous study also conducted in Ghana, [34] hepatitis B was perceived to be even more severe than HIV. This could be attributable to the fact that hepatitis B is not optimally managed in Ghana. Antiretroviral treatment for hepatitis B is not readily available and affordable,[16 44] the number of specialised clinics that can monitor and support PWHB is inadequate,[34] and the WHO policy on treatment, management, and support of PWHB in Ghana has not yet been implemented.[64 34]

Another finding of this study was the belief that hepatitis B is caused by curses. An earlier study has shown that people attach superstitious beliefs to hepatitis B in Ghana.[34] Also, a study conducted by Adjei et al. entitled "hepatitis B infection among perturient in Peri-Urban Ghana" 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 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.

In addition to documenting beliefs about hepatitis B that contribute to stigmatisation, we also explored manifestations of hepatitis B stigma. One manifestation was avoidance. This finding is consistent with other studies.[55 57] For example, in a study conducted in Japan with a sample of the working population, Eguchi and Wada[55] 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 body contact with close relations including kissing.[59]

In our study, we also found that stigma manifests as isolation and physical distance. Our finding that students were isolated from their counterparts 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 another somewhat earlier study by Yang and Wu,[65] 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. The findings showed that stigmatisation took form as excessive cautiousness, task-shifting and procedure avoidance, breaches of confidentiality, and silence by HCPs. Perhaps inadequate knowledge and fear of acquisition of HBV among the HCPs led to the excessive cautiousness and fear. This has been previously document by Yu and colleagues[66] 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 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 reflect in the beliefs about hepatitis B, we recommend public awareness campaigns that emphasize hepatitis B transmission routes. Also, given the manifestations of the stigma in the healthcare settings, we feel that a continuing professional development programme on the epidemiology of hepatitis B is called as this can enhance their knowledge in parallel to public awareness campaigns. Additionally, we recommend efforts to increase health literacy on hepatitis B prevention measures, including vaccination, as this may increase HCPs confidence when caring for PWHB. If developed based on both theory and evidence and in collaboration with target populations, these interventions have the potential to effectively reduce hepatitis B stigma in Ghana[67]

The findings of this study should be viewed in light of a few limitations. First, given the qualitative nature of the study, it is important to be cautious in generalising these findings. We therefore recommend following this study with a quantitative study that can quantify the extent to which hepatitis stigma is present in Ghana. Second, given that participants, particularly PWHB, were asked to retrospectively recall experiences, there is potential for recall bias in this study. We, however, sought to reduce this by asking follow-up questions to confirm or verify participants' experiences.

Conclusion

This study gives insight about beliefs contributing to hepatitis B stigma in Ghana and its manifestations. 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, isolation, and physical distance. In the healthcare settings, excessive cautiousness, task-shifting, procedure avoidance, breaches of confidentiality, and silence by HCPs were also found. We therefore 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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Abbreviation
HBV- Hepatitis B Virus; PWHB- People with Hepatitis B; HCPs – Healthcare Providers; IDI – In-depth Interviews; FGD – Focus Group Discussions

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Availability of data and materials: Participants have consented for anonymised transcripts to be shared upon request.

Authors Contribution: CAA conceptualised the study. CAA, SES, RACR, FN designed the study. Interview guide was designed by CAA and SES. Data analysis was done by CAA and SES. Manuscript was critically reviewed by SES, FN, RACR. All authors read and approved the manuscript.

Competing interests: The authors declare no conflict of interest in this study.
Consent for publication: Not applicable

Ethical Approval
Ethical clearance was obtained from Institutional Review Board of Korle-Bu Teaching Hospital (Approval number KBTH-IRB 00092/2016). Permission was sought from the management of the data collection sites, and informed consent (written) was obtained from the participants.

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Table 1: Socio-Demographic Data of Participants with Hepatitis B

Pseudonyms	Occupation	Year of Diagnosis	How participants were diagnosed
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 programme
PWHB 11	Unemployed	2010	Outreach programme
PWHB 12	Teacher	2015	Self-initiated
PWHB 13	Unemployed	2011	Hospital protocol for pregnant women
PWHB 14	Housewife	2014	Outreach 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 2: Socio-Demographic Data of Healthcare Providers

Pseudonyms	**Occupation**	**Year of practice**
HCP 1	Physician	4
HCP 2	Nurse	7
HCP 3	Nurse	9
HCP 4	Physicians	3
HCP 5	Nurse	2
HCP 6	Nurse	4
HCP 7	Physicians	5
HCP 8	Nurse	5
HCP 9	Physician	3

HCP 10	Nurse	9
HCP 11	Nurse	3
HCP 12	Physician	14
HCP 13	Physician	4
HCP 14	Physician	4
HCP 15	Physician	9
FGD 1	Nurse	10
FGD 2	Nurse	3
FGD 3	Nurse	5
FGD 4	Nurse	9
FGD 5	Nurse	11
FGD 6	Nurse	3
FGD 7	Nurse	4
FGD 8	Nurse	20
FGD 9	Nurse	9
FGD 10	Nurse	3
FGD 11	Nurse	11
FGD 13	Midwife	8
FGD 14	Nurse	4
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

Supplementary material 1: Interview Guide

PROTOCOL 1: HEPATITIS B RELATED STIGMA AND COPING INTERVIEW WITH PEOPLE WITH HEPATITIS B

1. **Introduction**

- Welcome the interviewee and appreciate their time for the session.
- Explain what the study is about.
- Explain what the interview involves including the specific topics to be discussed.
- Inform the interviewee about confidentiality.
- Tell the interviewee that the discussion will be recorded and explain the rationale.
- Discuss voluntary participation- emphasize on their right to stop at any time without consequences.
- Give interviewee opportunity to ask questions including concerns.
- Signing of informed consent form by participant.
- Switch on audio-recorder.

2. **Background Information**
   - ✓ Age
   - ✓ Gender
   - ✓ Marital Status
   - ✓ Occupation
   - ✓ Year first diagnosed with HBV infection
   - ✓ How participant got tested (self-request, general screening exercise, recommendation by physician, employment requirement, pre-marital requirement etc.)
3. **Experience of Stigma and Its Manifestations**

a. Can you share with me about a situation in which you were treated differently (stigma), or discriminated against because of your HBV positive status? Probe
b. Where were you treated differently? **Probe**
c. How often have you experienced this including negative reaction?
d. What do you think causes people to treat you differently? **Probe**
e. What do you think society perceive people with hepatitis B as? **Probe**
f. How did these experiences affect you? **Probe**

PROTOCOL 2: INTERVIEW OF HEALTHCARE PROVIDERS

1. Have you attended to someone with hepatitis B infection before?
2. If yes, can you share your experience/reaction with me? **Probe**
3. What do society perceive hepatitis B as? **Probe**
4. What do people perceive individuals with hepatitis B infection as? **Probe**

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	5
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1
Occupation	3	What was their occupation at the time of the study?	1
Gender	4	Was the researcher male or female?	1
Experience and training	5	What experience or training did the researcher have?	1
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	NO
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	4
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	5
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	1
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	1
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	4
Sample size	12	How many participants were in the study?	1
Non-participation	13	How many people refused to participate or dropped out? Reasons?	4
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	4
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	NO
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	4
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	5
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	NO
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	5
Field notes	20	Were field notes made during and/or after the inter view or focus group?	5
Duration	21	What was the duration of the inter views or focus group?	5
Data saturation	22	Was data saturation discussed?	5
Transcripts returned	23	Were transcripts returned to participants for comment and/or	15

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	5
Description of the coding tree	25	Did authors provide a description of the coding tree?	NO
Derivation of themes	26	Were themes identified in advance or derived from the data?	5
Software	27	What software, if applicable, was used to manage the data?	5
Participant checking	28	Did participants provide feedback on the findings?	15
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	6-13
Data and findings consistent	30	Was there consistency between the data presented and the findings?	6-13
Clarity of major themes	31	Were major themes clearly presented in the findings?	6, 8
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	6-13

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The challenge of stigma among people with chronic Hepatitis B in Ghana: a qualitative study

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ABSTRACT

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

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 version 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 and 47 healthcare providers (primary care physicians, nurses, and midwives) between the ages of 21 and 57 years participated in the study.

Results: The findings of the study showed that people with chronic Hepatitis B are faced with stigma in their socio-cultural 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). Also, in healthcare settings, excessive cautiousness, task-shifting, procedure avoidance, and breaches of confidentiality were reported.

Conclusions: Given the prevalence of incorrect knowledge, as reflect 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 believe that a continuing professional development programme on the aetiology of Hepatitis B is called as this can enhance the knowledge of the healthcare providers in parallel to public awareness campaigns. Also, effective theory and evidence-based stigma reduction interventions are recommended.

Key words: Stigma, challenge, chronic Hepatitis B, infection, Ghana.

Strengths and limitations of this study

- This study is the first to document Hepatitis B stigma in Ghana.
- Triangulation of the data across different settings, people with chronic Hepatitis B and different categories of healthcare providers (primary physicians, nurses, and midwives) assisted in understanding and describing the phenomenon in terms of depth and breadth 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.

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 (i.e. hepatocellular carcinoma and cirrhosis) were recorded in 2015.[2] Sub-Saharan Africa is disproportionately affected [2] 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] [7-12] 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, and intimate 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, diseases with some risk of transmission are associated with stigma.[17 18] This is well reported for conditions such as tuberculosis, HIV, and mental illnesses.[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 Phelan[31] 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 dominate or exploit another by virtue of their wealth, power and high social status. On the other hand, enforcement of social norm centres on written and unwritten rules that people are expected to follow and violaters of these norms suffer the consequences.[31] However, because Hepatitis B is an infectious disease, disease avoidance as a motivation for stigmatisation is likely. This is supported by evidence from Canada and Pakistan showing that PWHB experience diverse degrees of stigma because of the perceived infectiousness of HBV.[32-33] Stigmatisation may also 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] In additon, ignorance about HBV routes of transmission is documented to contributes to Hepatitis B stigma.[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 health care settings.[38 39] For example, Wada and colleagues[38] 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 many consequences. It has been found to create an environment of secrecy and denial, can lead to depression, and can be a barrier to health care 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 one's HBV status can be a barrier to preventing transmission to others.[44] Further, stigmatisation can serve to deter people at risk for HBV infection from being 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 the perspectives of PWHB and HCPs on the beliefs contributing to Hepatitis B stigma in Northern and Southern Ghana and the ways in which Hepatitis B stigma manifests. Understanding this phenomenon is important as it can

inform the design of effective Hepatitis B and stigma prevention interventions and 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] Ethical approval was given by the Korle-Bu Institutional Review Board (Approval number KBTH-IRB 00092/2016).

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 ten 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 out-patient cases in regional hospitals. One tertiary hospital in the south and one regional hospital in the North were selected for the study. In most Ghanaian societies, people attach different beliefs to the cause of their illness depending on their religious affiliation. For example, Christians and Moslems recognise God as the one who controls life events and also has the power to deliver people from bad situations including illnesses. On the other hand, those with traditional beliefs also attribute the cause of unusual event 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, some of the manifestations of stigma occur in the clinical setting and therefore we believed that they were in a better position to share those experiences with us.

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 the disease and had less energy to go through the interview session were excluded. However, only one person in the terminal stage of the disease was seen in the tertiary hospital but was not recruited because he was in a state of dyspnoea

(breathlessness). Also, HCPs who had less than three months working experience in a department where services are provided for PWHB were excluded as these HCPs might not have enough experience with Hepatitis B.

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 also recruited directly through nurses at the health facilities. PWHB recruited through the advertisement were 6 and the remaining 12 were recruited through nurses in the hospitals. On the other hand, 10 HCPs were recruited through advertisement and 37 of the HCPs were recruited through nurses in the hospitals. Overall, 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. Another 5 HCPs did not honour the invitation as a result of an emergency call at work or conflicting schedule with other unplanned social events. PWHB participated in semi-structured in-depth interviews. HCPs were either interviewed or participated in a focus group discussion (FGD). The combination of interviews and FGD for HCP assisted in understanding and describing the phenomenon comprehensively in terms of depth and breadth and further ensured the trustworthiness of the findings (Lambert & Loiselle, 2008). However, given the sensitive nature of the topic and the extent to which responses to the study questions could be quite personal for PWHB, PWHB were not recruited for FGDs. Interviews were deemed more appropriate.[52] The interviews and FGD were conducted by the first author (CAA) who is a PhD student with a good background in qualitive data collection including interviews and FGD. He is also fluent in English and the local Ghanaian language (Twi) but all interviews and FGD were done in English. Two days before the interview/FGD, participants were contacted by telephone to remind them of the appointment. The interviews/FGDs were conducted mostly in the homes of those 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 interview/FGD. 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, 4 FGD with a composition of 8 HCPs in each group were conducted. The interviews involving PWHB and HCPs lasted between 45 minutes and 1 hour whereas the FGDs with HCPs lasted approximately 1 hour and 15 minutes. Data saturation was reached after the interview of the 14th PWHB and 12th HCP.[53]

Research Instrument

The interview and FGD were guided by a semi-structured protocol with the flexibility to probe. The protocol was developed based on empirical literature on Hepatitis B stigma[54] 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 include (1) participants experiences being treated poorly or differently because of their HBV sero-positivity and the settings in which those experiences took place (2) perceived reasons for being treated poorly or differently (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 and, their reactions (3) possible reasons for negative reactions to PWHB. A detailed interview protocol can be found in the supplementary material 1.

Data Analysis

Data were processed with QSR Nvivo version 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, categories, and themes generated. At the end, a consensus was reached on the codes, and the main themes and sub-themes were documented. Preliminary findings were checked with two representatives of the study population to confirm if the findings were in lines with their views and experiences. Two main themes and eight sub-themes emerged from the data (summary presented in table 1).

Patient/Public Involvement

Patients and the public were not involved in the development of the research questions, the design, recruitment, and conduct of the study. The study results will be shared with the participants and other relevant stakeholders through various social media handles, and conference presentations.

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 the infection 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 socio-demographic 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. Additionally, it is sometimes associated with curses. These themes are described in detail below.

Hepatitis B as highly contagious

It was widely reported by participants with Hepatitis B 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 an infected person. These 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,

"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 [1])

Another participant with chronic Hepatitis B also recounted his experience in school,

"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. She said,

"There is a lot of false information about Hepatitis B in the public domain which put 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)

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 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

[1] All names have been changed to protect the identity of participants

easy identification and notification. Also, HCPs reported treating PWHB differently because they fear possible infection. Some of the reactions from HCP are as follows,

"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)

Fear of infection on the part of HCPs was also said to result in patients with chronic Hepatitis B being neglected by some HCPs.

"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 three 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)

Hepatitis B as very severe

Participants also indicated that many people think Hepatitis B is not only easily transmittable but very severe. Hepatitis B was claimed to be seen as a condition with poor prognosis which eventually leads to death. One participant with chronic Hepatitis B shared her view,

"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).

Participants emphasized the severity by comparing Hepatitis B to HIV/AIDS as illustrated by this quote: "*People say it is deadly, it kills faster than HIV/AIDS."* (HCP, South-IDI 12)
A belief that was said to contribute to the perceived severity of Hepatitis B is the belief that Hepatitis B is 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)

Hepatitis B as a curse

Another belief held about Hepatitis B is that it affects people who have been cursed for their 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 the Ghanaian context. According to a number of the participants, people in their community believe that the swollen abdomen and feet that characterise Hepatitis B suggest that those infected are cursed for not respecting or taking care of their parents. This was vividly reported by some HCPs in Northern Ghana where tradition and culture are highly upheld.

"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 health care 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 an HCP revealed some of the rituals that are performed in the healthcare settings before the corpse of someone with chronic Hepatitis B is taken out for a burial. This according to the participant is done to prevent possible transmission of the disease to the family members of the deceased.

She said,

"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, both in general and specifically in healthcare settings.

Avoidance

Participants reported various ways in which stigmatisation was expressed toward PWHB. Avoidance was a typical reaction reported. A participant with chronic Hepatitis B recounted her experience following diagnosis and disclosure of her status to her close relation.

"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 said,

"Hmmmm! *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)

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 was said to be based on speculations. People who were known or suspected to have a sexual relationship with persons with Hepatitis B were also said to be 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,

"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)

Social isolation

Participants also reported social isolation as manifestations of stigma. They reported that, in some senior high schools where students reside in the dormitories, those with chronic Hepatitis B are isolated form 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,

"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 confined to their rooms. They are treated as outcasts and have many social restrictions. Additionally, it was reported that some PWHB have family roles taken from them and are denied participation in family functions. A participant with chronic Hepatitis B shared her observations,

"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)

The social isolation of PWHB was also reported to occur in the healthcare settings as well. In this context, social isolation occurred because, according to the 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)

Another PWHB shared his thoughts,

"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)

The public reaction toward PWHB was said to worsen when they 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)

Furthermore, participants indicated that family members sometimes distance themselves because they consider it as way of escaping the wrath of the gods, reflecting again the belief that Hepatitis B is 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)

Stigmatisation in health care settings

Specific manifestations of stigma in health care settings were reported as well. There, stigma not only manifested as avoidance and social isolation as outlined above, but also as excessive cautiousness, task-shifting, procedure avoidance, and breaches of confidentiality.

Excessive cautiousness by HCPs

Participants reported that excessive cautiousness was taken by HCPs when provided 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 gloves 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 the negative perception about Hepatitis B compromises, to some extent, the quality of care individuals with chronic Hepatitis B are expected to 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)

Task-shifting and procedure avoidance

The majority of the HCPs indicated that postponement of procedures and task shifting are common when caring for PWHB. In some instances, HCPs failed to perform nursing procedures but, rather, delayed care when the patient was identified as having chronic Hepatitis B. This too 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 said,

"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)

A number of the participants indicated that some HCPs shift their tasks such that student nurses have to perform them. A nurse recounted her experience during her formal clinical training,

"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)

Another nurse said,

"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 manifestations of stigma that were reported to occur in healthcare settings was breaches of confidentiality. Participants reported that some HCPs indeed fail to maintain confidentiality. According to some participants, 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 the perspectives of PWHB and HCPs on the beliefs contributing to Hepatitis B stigma in Northern and Southern Ghana and the ways in which Hepatitis B stigma manifests. Our findings show 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. Our findings also show that Hepatitis B stigmatisation manifests as avoidance and social isolation. In the healthcare setting, excessive cautiousness, task-shifting, procedure avoidance, and breaches of confidentiality were also reported.

The belief that Hepatitis B is highly contagious was reported by both PWHB and HCPs as central to the existence of 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 chronic Hepatitis B infected persons 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.[26 33 42 55 56-59] For example, in Parkistan, Rafique and colleagues[33] indicated that PWHB suffered 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 claimed to be be an important source of HBV transmission thus leading to avoidance of PWHB has also previously been documented by a study conducted in Nigeria.[60] That sweat is in fact not a vehicle for HBV transmission[61] suggests a knowledge deficit regarding Hepatitis B transmission not only among the general public in Ghana but also 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 contributes to stigmatisation. Generally, participants perceived Hepatitis B as deadly. This is consistent with a study conducted by Upadhyaya et al.[63] in the United State. In that study Upadhyaya and colleagues assessed the role and attitude of primary care physicians in Hepatitis B diagnosis and treatment. They found that physicians perceived Hepatitis B as very serious.[63] Interestingly, in our study and previous study also conducted in Ghana, [34] Hepatitis B was perceived to be even more severe than HIV. This could be attributable to the fact that Hepatitis B is not optimally managed in Ghana. Unlike in the case of HIV, antiretroviral treatment for Hepatitis B is not readily available and affordable,[16 44] the number of specialised clinics that can monitor and support PWHB is inadequate,[34] and the WHO policy on treatment, management, and support of PWHB in Ghana has not yet been implemented.[64 34]

Additionally, 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. The only national policy on Hepatitis B prevention in Ghana is the administation of Hepatitis B pentavlent vaccine to newborns at the 6, 10, 14 weeks after birth.[34]

Another finding of this study was the belief that Hepatitis B is caused by curses. An earlier study has shown that people attach superstitious beliefs to Hepatitis B in Ghana.[34] Also, a study conducted by Adjei et al. entitled "Hepatitis B infection among perturient in Peri-Urban Ghana" 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 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.

In addition to documenting beliefs about Hepatitis B that contribute to stigmatisation, we also explored manifestations of Hepatitis B stigma. One manifestation was avoidance. This finding is consistent with other studies.[55 57] For example, in a study conducted in Japan with a sample of the working population, Eguchi and Wada[55] 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 body 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 their counterparts 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 another somewhat earlier study by Yang and Wu,[65] 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. The findings showed that stigmatisation took form as excessive cautiousness, task-shifting and procedure avoidance, and breaches of confidentiality. Perhaps inadequate knowledge and fear of acquisition of HBV among the HCPs led to the excessive cautiousness and fear. This has been previously document by Yu and colleagues[66] 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 reflect in the beliefs about Hepatitis B, we recommend public awareness campaigns that emphasize Hepatitis B transmission routes. Also, given the manifestations of the stigma in the healthcare settings, we feel that a continuing professional development programme on the aetiology of Hepatitis B is called as this can enhance HCPs knowledge in parallel to public

awareness campaigns. Additionally, we recommend efforts to increase health literacy on Hepatitis B prevention measures, including vaccination, as this may increase HCPs confidence when caring for PWHB. If developed based on both theory and evidence and in collaboration with target populations, these interventions have the potential to effectively reduce Hepatitis B stigma in Ghana.[67] In addition, PWHB should be counsel on the relevance of using either problem focused coping strategies such as seeking social support, affiliating with others with same disease and emotion-focused strategies such as religious coping and positive reappraisal as a way of building their resilience.[19] [68] Stigma reduction intervention such as psycho-educational intervention which focuses on education, skill building, empowerment, and social support can be explored in Ghana.[69]

The findings of this study should be viewed in light of a few limitations. 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. Second, given that participants, particularly PWHB had lived with the infection for a period between one and seven 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 limitation of this study is the exclusion of PWHB who were in the terminal stage of the disease. We therefore recognise that their experiences with stigma might differ from our study participants.

Conclusion

This study gives insight about beliefs contributing to Hepatitis B stigma in Ghana and its manifestations. 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, excessive cautiousness, task-shifting, procedure avoidance, and breaches of confidentiality were also found. We therefore 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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Abbreviation

HBV- Hepatitis B Virus; PWHB- People with Hepatitis B; HCPs – Healthcare Providers; IDI – In-depth Interviews; FGD – Focus Group Discussions

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Ethical Approval
Ethical clearance was obtained from Institutional Review Board of Korle-Bu Teaching Hospital (Approval number KBTH-IRB 00092/2016). Permission was sought from the management of the data collection sites, and informed consent (written) was obtained from the participants.

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Table 1: Summary of themes and sub-themes

Themes	Sub-themes
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
	Task-shifting and procedure avoidance
	Breaches of confidentiality

Table 2: Socio-Demographic Data of Participants with Chronic Hepatitis B

Pseudonyms	Occupation	Year of Diagnosis	How participants were diagnosed
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 programme
PWHB 11	Unemployed	2010	Outreach programme
PWHB 12	Teacher	2015	Self-initiated
PWHB 13	Unemployed	2011	Hospital protocol for pregnant women
PWHB 14	Housewife	2014	Outreach 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: Socio-Demographic Data of Healthcare Providers

Pseudonyms	Occupation	Year of practice
HCP 1	Physician	4
HCP 2	Nurse	7
HCP 3	Nurse	9
HCP 4	Physicians	3
HCP 5	Nurse	2
HCP 6	Nurse	4
HCP 7	Physicians	5
HCP 8	Nurse	5
HCP 9	Physician	3
HCP 10	Nurse	9
HCP 11	Nurse	3
HCP 12	Physician	14
HCP 13	Physician	4
HCP 14	Physician	4
HCP 15	Physician	9
FGD 1	Nurse	10
FGD 2	Nurse	3
FGD 3	Nurse	5
FGD 4	Nurse	9
FGD 5	Nurse	11

FGD 6	Nurse	3
FGD 7	Nurse	4
FGD 8	Nurse	20
FGD 9	Nurse	9
FGD 10	Nurse	3
FGD 11	Nurse	11
FGD 13	Midwife	8
FGD 14	Nurse	4
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

Supplementary material 1: Interview Guide

PROTOCOL 1: HEPATITIS B RELATED STIGMA AND COPING INTERVIEW WITH PEOPLE WITH HEPATITIS B

1. **Introduction**

- Welcome the interviewee and appreciate their time for the session.
- Explain what the study is about.
- Explain what the interview involves including the specific topics to be discussed.
- Inform the interviewee about confidentiality.
- Tell the interviewee that the discussion will be recorded and explain the rationale.
- Discuss voluntary participation- emphasize on their right to stop at any time without consequences.
- Give interviewee opportunity to ask questions including concerns.
- Signing of informed consent form by participant.
- Switch on audio-recorder.

2. **Background Information**
   - ✓ Age
   - ✓ Gender
   - ✓ Marital Status
   - ✓ Occupation
   - ✓ Year first diagnosed with HBV infection
   - ✓ How participant got tested (self-request, general screening exercise, recommendation by physician, employment requirement, pre-marital requirement etc.)
3. **Experience of Stigma and Its Manifestations**

a. Have you been treated differently because you have hepatitis B?
b. If yes, can you share with me about a situation in which you were treated differently (stigma), or discriminated against because of your HBV positive status? Probe
c. Where were you treated differently? **Probe**
d. How often have you experienced this including negative reaction?
e. What do you think causes people to treat you differently? **Probe**
f. What do you think society perceive people with hepatitis B as? **Probe**
g. How did these experiences affect you? **Probe**

PROTOCOL 2: INTERVIEW OF HEALTHCARE PROVIDERS

1. Have you attended to someone with hepatitis B infection before?
2. If yes, can you share your experience/reaction with me? **Probe**
3. What do society perceive hepatitis B as? **Probe**

4. What do people perceive individuals with hepatitis B infection as? **Probe**

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	5
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1
Occupation	3	What was their occupation at the time of the study?	1
Gender	4	Was the researcher male or female?	1
Experience and training	5	What experience or training did the researcher have?	1
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	NO
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	4
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	5
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	1
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	1
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	4
Sample size	12	How many participants were in the study?	1
Non-participation	13	How many people refused to participate or dropped out? Reasons?	4
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	4
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	NO
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	4
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	5
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	NO
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	5
Field notes	20	Were field notes made during and/or after the inter view or focus group?	5
Duration	21	What was the duration of the inter views or focus group?	5
Data saturation	22	Was data saturation discussed?	5
Transcripts returned	23	Were transcripts returned to participants for comment and/or	15

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	5
Description of the coding tree	25	Did authors provide a description of the coding tree?	NO
Derivation of themes	26	Were themes identified in advance or derived from the data?	5
Software	27	What software, if applicable, was used to manage the data?	5
Participant checking	28	Did participants provide feedback on the findings?	15
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	6-13
Data and findings consistent	30	Was there consistency between the data presented and the findings?	6-13
Clarity of major themes	31	Were major themes clearly presented in the findings?	6, 8
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	6-13

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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

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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 version 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 and 47 healthcare providers (primary care physicians, nurses, and midwives) between the ages of 21 and 57 years participated in the study.

Results: People with chronic Hepatitis B face stigma in their socio-cultural 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 HCPs.

Key words: Hepatitis B, Ghana, stigma, beliefs.

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.

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 (i.e. hepatocellular carcinoma and cirrhosis) were recorded in 2015.[2] Sub-Saharan Africa is disproportionately affected [2] 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 7-12] 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 Phelan[31] 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 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 stigmatized.[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 tranmitted through intimate sexual contact, the enforcement of social norms as a motivation for stigmatization could be particularly relevant in Ghana, where the majority of the population are Chritians and Muslims who disapprove of pre-marital sex.[34] In addition, a lack of knowledge about HBV routes of transmission has been found to also contributes 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 colleagues[38] 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 health care 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 people with chronic Hepatitis B as well 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] Ethical approval was given by the Korle-Bu Institutional Review Board (Approval number KBTH-IRB 00092/2016). 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 ten 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 out-patient 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 one who controls life events and one who 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 three 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, 6 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 5 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 semi-structured in-depth interviews. HCPs were either interviewed or participated in a focus group discussion (FGD). The combination of interviews and FGD for HCP assisted in understanding and describing the phenomenon comprehensively and further ensured the trustworthiness of the findings[52]. One important observation that was made during the FGD was that the participant's built on the ideas of their colleagues which added some details to the data. In fact, the use of the FGD 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, PWHB were not recruited for FGDs. Interviews were deemed more appropriate.[53]

The interviews and FGD were conducted by the first author (CAA) who is a PhD candidate with a background in qualitative research including conducting and analysing interviews and FGD. He is also fluent in English and the local Ghanaian language (Twi) but all interviews and FGD were done in English. Two days before the interview/FGD, participants were contacted by telephone to remind them of the appointment. The interviews/FGDs were conducted mostly in the homes of those 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 interview/FGD. 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, 4 FGD with a composition of 8 HCPs in each group were conducted. The interviews involving PWHB and HCPs lasted between 45 minutes and 1 hour whereas the FGDs with HCPs lasted approximately 1 hour and 15 minutes. Data saturation was reached after the interview of the 14th PWHB and 12th HCP.[52]

Research Instrument

The interview and FGD were guided by a semi-structured protocol with the flexibility to probe. The protocol was developed based on empirical literature on Hepatitis B stigma[54] 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 sero-positivity 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 supplementary material 1.

Data Analysis

Data were processed with QSR Nvivo version 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 sub-themes 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 sub-themes emerged from the data. These are summarised in Table 1.

Patient/Public Involvement

Patients and the public were not involved in the development of the research questions, the design, recruitment, and conduct of the study. The study results will be shared with the participants and other relevant stakeholders through various social media handles, and conference presentations.

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 socio-demographic 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. 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 [1])

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,

[1] All names have been changed to protect the identity of participants

"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 not only easily transmitted but also 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 emphasized 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 health care 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 participants 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 form 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 health care settings

Specific manifestations of stigma in health care settings were reported as well. In healthcare settings, stigma was reported to not only manifest as avoidance and social isolation as outlined above, but also 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 compromises, 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 three 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 people with chronic Hepatitis B as well 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 people with chronic Hepatitis B 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 55 56-59] For example, in Parkistan, Rafique and colleagues[33] 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 transmission[61] and this suggests a knowledge deficit regarding Hepatitis B transmission not only among the general public in Ghana but also 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 United States, 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 Ghana[34] 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 inadequate[34] and the WHO policy on treatment, management, and support of PWHB in Ghana has not yet been implemented.[65 34] 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 administation 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.[55 57] For example, in a study conducted in Japan with a sample of the working population, Eguchi and Wada[55] 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 an study by Yang and Wu[67] 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 use excessive precautions due to fear of acquisition of HBV by the HCPs found in this study has been previously documented by Yu and colleagues[68] 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 emphasize 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 program, 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 stigmatization.[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 one and seven 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.

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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Abbreviation

HBV- Hepatitis B Virus; PWHB- People with Hepatitis B; HCPs – Healthcare Providers; IDI – In-depth Interviews; FGD – Focus Group Discussions

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Ethical clearance was obtained from Institutional Review Board of Korle-Bu Teaching Hospital (Approval number KBTH-IRB 00092/2016). Permission was sought from the management of the data collection sites, and informed consent (written) was obtained from the participants.

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Table 1: Summary of themes and sub-themes

Themes	Sub-themes
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

Table 2: Socio-demographic data of participants with chronic Hepatitis B

Pseudonyms	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: Socio-Demographic 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

Supplementary material 1: Interview Guide

PROTOCOL 1: HEPATITIS B RELATED STIGMA AND COPING INTERVIEW WITH PEOPLE WITH HEPATITIS B

1. **Introduction**

- Welcome the interviewee and appreciate their time for the session.
- Explain what the study is about.
- Explain what the interview involves including the specific topics to be discussed.
- Inform the interviewee about confidentiality.
- Tell the interviewee that the discussion will be recorded and explain the rationale.
- Discuss voluntary participation- emphasize on their right to stop at any time without consequences.
- Give interviewee opportunity to ask questions including concerns.
- Signing of informed consent form by participant.
- Switch on audio-recorder.

2. **Background Information**
   - ✓ Age
   - ✓ Gender
   - ✓ Marital Status
   - ✓ Occupation
   - ✓ Year first diagnosed with HBV infection
   - ✓ How participant got tested (self-request, general screening exercise, recommendation by physician, employment requirement, pre-marital requirement etc.)
3. **Experience of Stigma and Its Manifestations**

a. Have you been treated differently because you have hepatitis B?
b. If yes, can you share with me about a situation in which you were treated differently (stigma), or discriminated against because of your HBV positive status? Probe
c. Where were you treated differently? **Probe**
d. How often have you experienced this including negative reaction?
e. What do you think causes people to treat you differently? **Probe**
f. What do you think society perceive people with hepatitis B as? **Probe**
g. How did these experiences affect you? **Probe**

PROTOCOL 2: INTERVIEW OF HEALTHCARE PROVIDERS

1. Have you attended to someone with hepatitis B infection before?
2. If yes, can you share your experience/reaction with me? **Probe**
3. What do society perceive hepatitis B as? **Probe**

4. What do people perceive individuals with hepatitis B infection as? **Probe**

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	5
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1
Occupation	3	What was their occupation at the time of the study?	1
Gender	4	Was the researcher male or female?	1
Experience and training	5	What experience or training did the researcher have?	1
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	NO
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	4
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	5
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	1
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	1
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	4
Sample size	12	How many participants were in the study?	1
Non-participation	13	How many people refused to participate or dropped out? Reasons?	4
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	4
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	NO
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	4
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	5
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	NO
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	5
Field notes	20	Were field notes made during and/or after the inter view or focus group?	5
Duration	21	What was the duration of the inter views or focus group?	5
Data saturation	22	Was data saturation discussed?	5
Transcripts returned	23	Were transcripts returned to participants for comment and/or	15

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	5
Description of the coding tree	25	Did authors provide a description of the coding tree?	NO
Derivation of themes	26	Were themes identified in advance or derived from the data?	5
Software	27	What software, if applicable, was used to manage the data?	5
Participant checking	28	Did participants provide feedback on the findings?	15
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	6-13
Data and findings consistent	30	Was there consistency between the data presented and the findings?	6-13
Clarity of major themes	31	Were major themes clearly presented in the findings?	6, 8
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	6-13

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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

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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 version 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 and 47 healthcare providers (primary care physicians, nurses, and midwives) between the ages of 21 and 57 years participated in the study.

Results: People with chronic Hepatitis B face stigma in their socio-cultural 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 HCPs.

Key words: Hepatitis B, Ghana, stigma, beliefs.

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.

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 (i.e. hepatocellular carcinoma and cirrhosis) were recorded in 2015.[2] Sub-Saharan Africa is disproportionately affected [2] 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] [7-12] 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 Phelan[31] 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 stigmatized.[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 stigmatization could be particularly relevant in Ghana, where the majority of the population are Christians and Muslims who disapprove of pre-marital 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 colleagues[38] 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 health care 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 people with chronic Hepatitis B as well 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] Ethical approval was given by the Korle-Bu Institutional Review Board (Approval number KBTH-IRB 00092/2016). 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 ten 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 out-patient 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 three 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, 6 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 5 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 semi-structured 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, PWHB 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, 4 FGDs with a composition of 8 HCPs in each group were conducted. The interviews involving PWHB and HCPs lasted between 45 minutes and 1 hour whereas the FGDs with HCPs lasted approximately 1 hour and 15 minutes. 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 semi-structured protocol with the flexibility to probe. The protocol was developed based on empirical literature on Hepatitis B stigma[54] 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 sero-positivity 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 supplementary material 1.

Data Analysis

Data were processed with QSR Nvivo version 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 was 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 sub-themes 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 sub-themes emerged from the data. These are summarised in Table 1.

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 socio-demographic 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. 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 [1])

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,

[1] All names have been changed to protect the identity of participants

"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 not only easily transmitted but also 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 emphasized 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 health care 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 form 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 health care settings

Specific manifestations of stigma in health care settings were reported as well. In healthcare settings, stigma was reported to not only manifest as avoidance and social isolation as outlined above, but also 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 compromises, 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 three 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 people with chronic Hepatitis B 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 people with chronic Hepatitis B 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 55 56-59] For example, in Parkistan, Rafique and colleagues[33] 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 transmission[61] and this suggests a knowledge deficit regarding Hepatitis B transmission not only among the general public in Ghana but also 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 United States, 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 Ghana[34] 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 inadequate[34] and the WHO policy on treatment, management, and support of PWHB in Ghana has not yet been implemented.[65 34] 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 administation 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.[55 57] For example, in a study conducted in Japan with a sample of the working population, Eguchi and Wada[55] 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 an study by Yang and Wu[67] 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 use excessive precautions due to fear of acquisition of HBV by the HCPs found in this study has been previously documented by Yu and colleagues[68] 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 emphasize 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 program, 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 stigmatization.[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 one and seven 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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Abbreviation

HBV- Hepatitis B Virus; PWHB- People with Hepatitis B; HCPs – Healthcare Providers; IDI – In-depth Interviews; FGDs – Focus Group Discussions

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Table 1: Summary of themes and sub-themes

Themes	Sub-themes
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

Table 2: Socio-demographic 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: Socio-Demographic 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

Supplementary material 1: Interview Guide

1. **Background Information**
   - ✓ Age
   - ✓ Gender
   - ✓ Marital Status
   - ✓ Occupation
   - ✓ Year first diagnosed with HBV infection
   - ✓ How participant got tested (self-request, general screening exercise, recommendation by physician, employment requirement, pre-marital requirement etc.)
2. **Experience of Stigma and Its Manifestations**

a. Have you been treated differently because you have hepatitis B?
b. If yes, can you share with me about a situation in which you were treated differently (stigma), or discriminated against because of your HBV positive status? Probe
c. Where were you treated differently? **Probe**
d. How often have you experienced this including negative reaction?
e. What do you think causes people to treat you differently? **Probe**
f. What do you think society perceive people with hepatitis B as? **Probe**
g. How did these experiences affect you? **Probe**

PROTOCOL 2: INTERVIEW OF HEALTHCARE PROVIDERS

1. Have you attended to someone with hepatitis B infection before?
2. If yes, can you share your experience/reaction with me? **Probe**
3. What do society perceive hepatitis B as? **Probe**
4. What do people perceive individuals with hepatitis B infection as? **Probe**

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	5
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1
Occupation	3	What was their occupation at the time of the study?	1
Gender	4	Was the researcher male or female?	1
Experience and training	5	What experience or training did the researcher have?	1
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	NO
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	4
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	5
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	1
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	1
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	4
Sample size	12	How many participants were in the study?	1
Non-participation	13	How many people refused to participate or dropped out? Reasons?	4
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	4
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	NO
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	4
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	5
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	NO
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	5
Field notes	20	Were field notes made during and/or after the inter view or focus group?	5
Duration	21	What was the duration of the inter views or focus group?	5
Data saturation	22	Was data saturation discussed?	5
Transcripts returned	23	Were transcripts returned to participants for comment and/or	15

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	5
Description of the coding tree	25	Did authors provide a description of the coding tree?	NO
Derivation of themes	26	Were themes identified in advance or derived from the data?	5
Software	27	What software, if applicable, was used to manage the data?	5
Participant checking	28	Did participants provide feedback on the findings?	15
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	6-13
Data and findings consistent	30	Was there consistency between the data presented and the findings?	6-13
Clarity of major themes	31	Were major themes clearly presented in the findings?	6, 8
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	6-13

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.