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

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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

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3 settings, excessive cautiousness, task-shifting, procedure avoidance, breaches of
4 confidentiality, and silence by healthcare providers were reported.
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6 **Conclusions:** Implementation of programmes that increase public awareness about hepatitis
7 B transmission are needed in the study settings. Capacity training of healthcare providers on
8 epidemiology of hepatitis B is very crucial. Also, effective theory and evidence-based stigma
9 reduction interventions are recommended.
10

11 **Key words:** Stigma, challenge, hepatitis B, infection, Ghana.
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14 **Strengths and limitations of this study**

- 15
16 ➤ This study is the first to document hepatitis B stigma in Ghana. The outcome of this
17 study paves the way for future studies to measure quantitatively the extent of hepatitis
18 B stigma in the study context.
- 19
20
21 ➤ Triangulation of the data across people with hepatitis B and different categories of
22 healthcare providers (physicians, nurses, and midwives) added richness to the
23 findings. Also, the verbatim presentation of participants' views is a strength of this
24 study.
- 25
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27 ➤ The findings are limited by the small sample size and therefore one must be cautious
28 in generalising these findings to the entire population.
- 29
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31 ➤ We recognise the possibility of recall bias. However, this was reduced to some extent,
32 by asking follow-up questions to confirm participant's experiences.
33

34 **INTRODUCTION**

35
36 Hepatitis B viral (HBV) infection remains a public health challenge affecting approximately
37 248 million people worldwide.¹ Globally, about 887,000 deaths attributable to complications
38 of hepatitis B (i.e. hepatocellular carcinoma and cirrhosis) were recorded in 2015.² Sub-
39 Saharan Africa is disproportionately affected² as evidenced by the high HBV prevalence in
40 the region.³⁻⁶
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44 Within the Ghanaian context, several studies have estimated hepatitis B prevalence above
45 8%.^{3 7-12} In fact, the most recent prevalence estimate of hepatitis B in Ghana is 12.3%.³ HBV
46 transmission occurs through several means.^{1 13} In high endemic countries such as Ghana,
47 hepatitis B is predominantly transmitted perinatally.¹³ Other practices, including but not
48 limited to, unsafe injections, blood transfusions, dialysis, needle stick injuries, and intimate
49 non-sexual contact are postulated as a vehicle for HBV transmission.¹³ Perhaps, challenges
50 such as the high cost of testing and treatment, poor referral systems, a lack of HBV
51 management guidelines, and inadequate infrastructure for screening contribute to the high
52 prevalence of hepatitis B in developing countries, including Ghana.¹⁴⁻¹⁶
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3 Generally, diseases with some risk of transmission are associated with stigma.^{17 18} This is well
4 reported for conditions such as tuberculosis, HIV, and mental illnesses.¹⁹⁻²² Similarly, people
5 with hepatitis B (PWHB) are likely to be stigmatised.²³⁻²⁹ Stigmatisation is a socially and
6 culturally constituted process whereby a person is first labelled as different and then
7 devalued, leading to status loss and discrimination.^{30 31} Link and Phelan³¹ outlined three main
8 motivations for stigmatisation namely: exploitation and domination (keeping people down),
9 enforcement of social norms (keeping people in), and avoidance of diseases (keeping people
10 away). Because hepatitis B is an infectious disease, disease avoidance as a motivation for
11 stigmatisation is likely. This is supported by evidence from Canada and Pakistan showing
12 that PWHB experience diverse degrees of stigma because of the perceived infectiousness of
13 HBV.³²⁻³³ Stigmatisation may also be motivated by a desire to enforce social norms as
14 hepatitis B has been reported to be considered the consequence of promiscuous behaviour.²⁹
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^{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 colleagues³⁸ 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

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3 hepatitis B (under trees) and the workplace of HCPs (nurses stations and physician's
4 consulting rooms). The informed consent form was signed by all participants following an
5 explanation of the purpose of the study and explicit mention of the confidential and voluntary
6 nature of their participation. In addition, permission was sought from participants to record
7 the interview/FGD. Field notes were taken during the interviews and the FGDs.
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10 Data were collected between February and November 2017. In total, 18 in-depth interviews
11 were conducted with PWHB and 15 in-depth interviews with HCPs. Additionally, 4 FGD
12 with a composition of 8 HCPs in each group were conducted. The interviews involving
13 PWHB and HCPs lasted between 45 minutes and 1 hour whereas the FGDs with HCPs lasted
14 approximately 1 hour and 15 minutes. Data saturation was reached after the interview of the
15 14th PWHB and 12th HCP.⁵³
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20 **Research Instrument**

21 The interview and FGD were guided by a semi-structured protocol with the flexibility to
22 probe. The protocol was developed based on empirical literature on hepatitis B stigma and
23 then reviewed by an expert in stigma (SS). Subsequently, the interview protocol was piloted
24 with two PWHB and two HCPs. The interviews and FGD were conducted by the first author
25 (CAA) who is fluent in English and the local Ghanaian language (Twi) but all interviews and
26 FGD were done in English. Topics explored during the interviews with PWHB include (1)
27 participants experiences being treated poorly or differently because of their HBV sero-
28 positivity and the settings in which those experiences took place (2) perceived reasons for
29 being treated poorly or differently (3) the impact of those experiences. Topics explored in the
30 interviews and FGDs with HCPs were (1) perceptions about hepatitis B, (2) the extent to
31 which they have provided care to someone with hepatitis B and, their reactions (3) possible
32 reasons for negative reactions to PWHB. A detailed interview protocol can be found in the
33 supplementary material 1.
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39 **Data Analysis**

40 Data were processed with QSR Nvivo version 10.0 and analysed using content analysis.⁵⁴ The
41 first author (CAA) played and listened to the audio recordings and transcribed verbatim. The
42 first transcribed data were coded by two of the authors (CAA and SS) followed by
43 discussions on the individual codes, categories, and themes generated. At the end, a
44 consensus was reached on the codes, and the main themes and sub-themes were documented.
45 Two main themes and eight sub-themes emerged from the data. These are described in the
46 sections below.
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50 **Patient/Public Involvement**

51 Patients and the public were not involved in the development of the research questions, the
52 design, recruitment, and conduct of the study. The study results will be shared with the
53 participants and other relevant stakeholders through various social media handles, and
54 conference presentations.
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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 2¹)

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

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3 *“There is a lot of false information about hepatitis B in the public domain which put fear in*
4 *everyone. Some have the mind-set that you can get the virus from an infected person through*
5 *a handshake. This makes people alarmed when they know you have the virus.” (PWHB - IDI*
6 *11)*

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

11
12 *“I had a fourteen year old pregnant lady who had hepatitis B. I counselled her and the*
13 *mother. When they returned to the house, the father denied the girl opportunity to stay with*
14 *them to prevent others getting infected. The father thought that people with hepatitis B are*
15 *not supposed to eat with anyone and the person must use a separate bowl, cups etc. Based on*
16 *this, he could not accept the girl in the house for fear of passing on the infection to the entire*
17 *family.” (HCP - FGD 21)*

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21 The belief that hepatitis B is easily transmitted was also held by HCPs. Some reported that
22 because of this they have assigned unique names to hepatitis B positive clients for easy
23 identification and notification. Also, HCPs reported treating PWHB differently because they
24 fear possible infection. Some of the reactions from HCP are as follows,

25
26
27 *“I am a midwife and in the ward and we have given those with hepatitis B names. We call*
28 *them candidates. When we identify you as a candidate, most midwives don't want to touch*
29 *such a person. Even we ignore their money because we believe that where she kept the money*
30 *sweat could get to it and therefore we don't like it.” (HCP - FGD 13)*

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

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36
37 *“We had one hepatitis B case that came in a coma state and if you look at the severity of the*
38 *condition, most of the staff were not willing to provide any service for the patient. The patient*
39 *was restless and ended up losing his life after three days. After he died, nobody even wanted*
40 *to go closer to his dead body because we were afraid that we could be infected.” (HCP - IDI*
41 *10)*

42 43 44 **Hepatitis B as very severe**

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

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

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3 Another HCP said, *“People who are aware of hepatitis B know that it kills. They are very*
4 *cautious when they hear that someone has hepatitis B.”* (HCP - IDI 2).
5
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7 Participants emphasized the severity by comparing hepatitis B to HIV/AIDS as illustrated by
8 this quote: *“People say it is deadly, it kills faster than HIV/AIDS.”* (HCP – IDI 12)

9 A belief that was said to contribute to the perceived severity of hepatitis B is the belief that
10 hepatitis B is incurable.
11

12 *“What scares us is the information that hepatitis B has no cure. It therefore means that is*
13 *either you die with it or you live with it forever. HIV which is a popular disease seems to be*
14 *better than hepatitis B because there are drugs to keep you alive when you get it.”* (PWHB –
15 IDI 14)
16
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18 **Hepatitis B as a curse**

19 Another belief held about hepatitis B is that it affects people who have been cursed for their
20 wrong doing. This was reported to be based on the fact that people in advanced stages of
21 hepatitis B clinically present with ascites, jaundice, and oedema, and these presentations are
22 linked to punishment from gods in the Ghanaian context. According to a number of the
23 participants, people in their community believe that the swollen abdomen and feet that
24 characterise hepatitis B suggest that those infected are cursed. This was vividly reported by
25 some HCPs.
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30 *“Ascites [enlarged abdomen] and oedema [swollen feet] is one thing that society perceives as*
31 *caused by curses. Once they see it, they believe that the person has been cursed. The family*
32 *members don’t want to get closer since they feel that it is happening because of the person’s*
33 *bad deeds.”* (HCP - FGD 16)
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36 Participants spoke of how, in certain circumstances, family members seek alternative
37 treatment for hepatitis B when they are convinced that the gods are the cause of the
38 complications. They seek spiritual support and this often delays health care seeking. One
39 HCP recounted her experience with her father who had been hepatitis B positive.
40
41

42 *“My father had hepatitis B and died. He grew very lean, his stomach bloated and they said it*
43 *was a curse from the family. He wasn’t taken to the hospital and he was neglected by his*
44 *siblings. He was moved from one prayer camp to the other, one church to the other thinking*
45 *he would be cured but when he was brought back to the house, the infection was worse than*
46 *before. His eyes were very yellowish and he was very lean.”* (HCP – IDI 11)
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50 Furthermore, a report by an HCP revealed some of the rituals that are performed in the
51 healthcare settings before the corpse of someone with hepatitis B is taken out for a burial.
52 This according to the participant is done to prevent possible effect of the disease on the
53 family members of the deceased.
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55 She said,
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3 *“Sometimes when they [PWHB] die, the relatives perform some rituals to cleanse themselves*
4 *before the body is conveyed to the morgue.” (HCP – IDI 6)*
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6 **Manifestations of Stigma**

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8 In addition to reporting common beliefs about hepatitis B in Ghana, participants also reported
9 a number of ways in which hepatitis B stigma manifests, both in general and specifically in
10 healthcare settings.
11

12 **Avoidance**

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14 Participants reported various ways in which stigmatisation was expressed toward PWHB.
15 Avoidance was a typical reaction reported. A participant with hepatitis B recounted her
16 experience following diagnosis and disclosure of her status to her close relation.
17

18
19 *“As soon as they see that you have hepatitis B, they start avoiding you; something you pick,*
20 *they won’t pick; something you have used, they don’t want to get closer to it. At first, I used*
21 *to do things together with my uncle. Whenever he is eating, I can put my hand in it and eat*
22 *with him. After I told him that I was hepatitis B positive, he avoids me completely. Anytime he*
23 *returns from work he just greets me and enters his room. I don’t see him to chat and joke like*
24 *the way we used to.” (PWHB - IDI 3)*
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28 Another participant with hepatitis B also said,
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31 *“Hmmm! When my household members see me, they change their conversation. When they*
32 *are chatting and I go to sit down, then they get up. They treat you as if you have shit on*
33 *yourself. Everyone leaves you with so many excuses.” (PWHB – IDI 16)*
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35
36 Avoidance was also reported to occur in the healthcare settings. One HCP shared how she
37 avoided a colleague after learning she had hepatitis B.
38

39
40 *“I was working at one sub-district and the staff were friendly and so we were eating together.*
41 *One day, we were chatting and a colleague said, ‘She is hepatitis B positive’. From that day,*
42 *I never ate with them again because I felt uncomfortable. Knowing that the virus can be in*
43 *the saliva and there could be exchange of saliva while eating from the same bowl, I was*
44 *afraid of getting the infection so I stopped eating with them.” (HCP - FGD 8)*
45

46
47 Some of the avoidance was said to be based on speculations. People who were known or
48 suspected to have a sexual relationship with a hepatitis B positive individual were also said to
49 be avoided.
50

51
52 *“I was in a community health centre with subordinates who were young nurses. They were*
53 *eating together, doing everything together and very close until there was a death of a man. It*
54 *came out that the person died of hepatitis B and one of the nurses was said to be the*
55 *girlfriend. After the funeral, the girl was deserted. The eating together could not continue*
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3 *and, in fact, the girl became very worried and miserable because the relationship with her*
4 *colleagues changed.” (HCP - FGD 30)*
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6 Another participant narrated a similar experience,
7

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

19 Participants also reported isolation and increased physical distance as manifestations of
20 stigma. They reported that, in some senior high schools where students reside in the
21 dormitories, those with hepatitis B are isolated from their peers in an effort to prevent
22 possible transmission of the virus to other students. One HCP narrated an encounter she had
23 with a man, whose son suffered this treatment in school,
24
25

26
27 *“I met one man who was lamenting that his son in a senior high school was ejected from the*
28 *school dormitory because he tested hepatitis B positive. The boy has been isolated and now*
29 *sleeps in the classroom. The school authorities feel that, if they don’t isolate those who are*
30 *positive, they will end up infecting everybody and more students. Parents are compelled to*
31 *get houses outside school campus for such students.” (HCP - FGD 14)*
32
33

34 Participants also indicated that, in some parts of Northern Ghana, people who test hepatitis B
35 positive are confined to their rooms. They are treated as outcasts and have many social
36 restrictions. Additionally, it was reported that some PWHB have family roles taken from
37 them and are denied participation in family functions. A hepatitis B positive participant
38 shared her observations,
39
40

41 *“The person is isolated when family members are made aware of his/her hepatitis B positive*
42 *status. If they were cooking in one pot, the person ceases to cook with them. They give them*
43 *their own room and sometimes put the person very far away. They [PWHB] don’t move*
44 *around and always stay inside mourning their dead when not dead. They only come and*
45 *throw their food to them to take and eat. They won’t let you feel that you are also normal like*
46 *them.” (PWHB – IDI 8)*
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50 The social isolation of PWHB was also reported to occur in the healthcare settings as well. In
51 this context, isolation occurred because, according to the participants, people tend to believe,
52 as reported above, that an infected person can pass the infection to others through sweat. This
53 was claimed to motivate HCPs actions to separate PWHB from other clients. *“We put them*
54 *[PWHB] at the extreme corner where no one goes there.” (HCP - IDI 3)*
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4 Another PWHB shared his thoughts,
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6
7 *“Many people see those with hepatitis B as sources of infection because they think it can be*
8 *transmitted through sweat. They are sometimes afraid to go closer to them especially when*
9 *the person looks jaundiced (yellowish) and the stomach becomes big. Everyone becomes*
10 *scared and they may treat the person like a leper by distancing themselves from the person.”*
11 (PWHB – IDI 15)
12

13
14 The public reaction toward PWHB was said to worsen when they exhibit severe forms of
15 jaundice,
16

17
18 *“Some people feel that when you have hepatitis B and you look yellowish, it means that the*
19 *viruses are too many in your blood. At that point, everyone withdraws. When the person dies,*
20 *they don’t waste time to keep his/her body for proper funeral but quickly bury the person. I*
21 *have seen a number of cases like that in my village.”* (PWHB - IDI 3)
22
23

24 Furthermore, participants indicated that family members sometimes distance themselves
25 because they consider it as way of escaping the wrath of the gods, reflecting again the belief
26 that hepatitis B is a curse from the gods,
27

28
29 *“People fear to be closer to someone who has been cursed so they withdraw from the person*
30 *in order not to attract the anger of the gods.”* (HCP - FGD 27)
31
32

33 **Stigmatisation in health care settings**

34 Specific manifestations of stigma in health care settings were reported as well. There, stigma
35 not only manifested as avoidance, increased physical distance, and isolation as outlined
36 above, but also as excessive cautiousness, task-shifting, procedure avoidance, breaches of
37 confidentiality, and silence.
38
39

40 **Excessive cautiousness by HCPs**

41 Participants reported that excessive cautiousness was taken by HCPs when provided care to
42 clients with hepatitis B. This was evidenced by the use of extreme infection prevention
43 precautions. In some instances, HCPs stated that they wore extra gloves to prevent possible
44 acquisition of the virus,
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47
48 *“Anytime I am managing someone with hepatitis B, I am extra careful. I put on more than*
49 *one gloves and also wash my hands regularly.”* (HCP - FGD 20)
50
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52 Another HCP explained how this is related to the belief that hepatitis B is highly contagious,
53 *“When you get to know that the patient has hepatitis B infection, the mind-set changes*
54 *outright. You become very cautious because you are afraid of getting infected.”* (HCP - IDI
55 9)
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4 Notwithstanding, some HCPs indicated that their actions were dependent on the kind of
5 procedure.
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7
8 *“Sometimes it depends on what you are going to do for the person. For instance, when I am*
9 *going to empty the urine bag, I put on three gloves. But when I am feeding them, I don’t do*
10 *that because I know I am not coming into contact with anybody’s fluid.” (HCP - FGD 22)*
11

12
13 Some HCPs reported that their negative perception about hepatitis B compromises, to some
14 extent, their professional ethics.
15

16
17 *“I’ve seen a couple of cases where midwives were very careful not wanting to assist the*
18 *delivery of hepatitis B positive woman. Even the baby that was born, they were very sceptical*
19 *touching her and the mother. The way they handled them and the way they talked about it -*
20 *“whispering” when they are handing over - sometimes it is very obvious that they are*
21 *stigmatising the client.” (HCP- IDI 1)*
22

23 24 **Task-shifting and procedure avoidance**

25 The majority of the HCPs indicated that postponement of procedures and task shifting are
26 common when caring for PWHB. In some instances, HCPs failed to perform nursing
27 procedures but, rather, delayed care when the client was identified as having hepatitis B. This
28 too was reported to occur because of the perceived contagiousness of hepatitis B.
29

30
31 *“When we see them [PWHB] at the critical stage, some vomiting blood and coughing out*
32 *blood, you will see some nurses postponing procedures because they think that they can be*
33 *infected.” (HCP - FGD 5)*
34

35
36 Another participant said,

37
38 *“I ever sent a patient to the hospital. The intravenous line infiltrated and the nurses were*
39 *supposed to change it. I was amazed that no nurse was ready to do it. This nurse will say to*
40 *the other to go and do it. Another said let’s wait for the doctor and giggled. So I was getting*
41 *afraid. Is this person having HIV or what that no one seems interested working on him?”*
42 *(HCP - FGD 23)*
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44
45 A number of the participants indicated that some HCPs shift their tasks such that student
46 nurses have to perform them. A nurse recounted her experience during her formal clinical
47 training,
48

49
50 *“During our clinical placement, when cases like hepatitis B are admitted, it was we, the*
51 *students, that the nurses used to send to go and manage those clients. In fact, they won’t let*
52 *you know the exact condition until you cannot do something. Even that, when one of them is*
53 *coming to help you, the gloves will be more than five. Even with that, she will still come and*
54 *stand and say, “hold this place”, “do that”. She will not do it. So, if they begin to do that and*
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3 you also take the patient's folder and you see that it is hepatitis B, then you advise yourself"
4 (HCP - FGD 19)
5

6 Another nurse said,
7

8
9 *"During my first clinical attachment as a student nurse, hepatitis B patients were put in the*
10 *cubicle or an isolated veranda. Anytime they [nurses] were to attend to them, either during*
11 *dressing, checking of vital signs, it was student nurses that they ask us to go and do."* (HCP-
12 FGD 10)
13

14 **Breaches of confidentiality and silence**

15 Two final manifestations of stigma that were reported to occur in healthcare settings were
16 breaches of confidentiality and, conversely, silence, thus simply not discussing hepatitis B.
17 Participants reported that some HCPs indeed fail to maintain confidentiality. According to
18 some participants, it is common to receive information about PWHB from a colleague in the
19 various hospital wards and units.
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24 *"The moment they diagnose somebody hepatitis B positive, even if it is one single nurse who*
25 *is on duty, the whole hospital will hear. The nurse will circulate the information until that*
26 *ward nurses finish and everybody is informed. If the person is pregnant, it will even spread*
27 *to the antenatal unit and then to maternity ward and every nurse become careful with such a*
28 *person."* (HCP - FGD 28)
29

30
31 Conversely, silence on hepatitis B was reported as well. One participant explained the kind of
32 "silence" reactions that occurred in health care settings.
33

34
35 *"Personally I really feel disheartened during that moment when we are operating on*
36 *hepatitis B patients. The whole theatre setting becomes like a horror scene. The staff seem to*
37 *be afraid of possible infection. The room becomes quiet and the basic care becomes alarmed.*
38 *It's like hell has entered the theatre."* (HCP - IDI 1)
39
40

41 **DISCUSSION**

42
43 This study set out to explore the perspectives of PWHB and HCPs on the beliefs contributing
44 to hepatitis B stigma in Northern and Southern Ghana and the ways in which hepatitis B
45 stigma manifests. Our findings show three main beliefs underlie hepatitis B stigma in Ghana,
46 namely 1) the belief that hepatitis B is highly contagious; 2) the belief that hepatitis B is very
47 severe; and c) the belief that hepatitis B is caused by curses. Our findings also show that
48 hepatitis B stigmatisation manifests as avoidance, isolation, and physical distance. In the
49 healthcare setting, excessive cautiousness, task-shifting, procedure avoidance, breaches of
50 confidentiality, and silence by HCPs were also reported.
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54 The belief that hepatitis B is highly contagious was reported by both PWHB and HCPs as
55 central to the existence of stigma in Ghana. Contributing to this perceived contagiousness
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3 were beliefs that hepatitis B can be transmitted through casual contact such as handshaking,
4 touching, and the sharing of eating utensils with hepatitis B infected persons and a focus on
5 body fluids, such as sweat, as a source of infection. Stigmatisation originating from a fear of
6 infection is not particular to Ghana, but has been reported in other locations.^{26 33 42 55-59} For
7 example, in Pakistan, Rafique and colleagues³³ indicated that PWHB suffered stigmatising
8 reactions from their families who feared infection and thus refused to share eating and
9 drinking utensils, as well as soap and towels with relatives living with hepatitis B. That sweat
10 was claimed to be an important source of HBV transmission thus leading to avoidance of
11 PWHB has also previously been documented by a study conducted in Nigeria.⁶⁰ That sweat is
12 in fact not a vehicle for HBV transmission⁶¹ suggests a knowledge deficit regarding hepatitis
13 B transmission not only among the general public in Ghana but also among HCPs. This is
14 particularly disconcerting given that HCPs are considered an important source of hepatitis B
15 information by their clients.⁶²

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

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34 Another finding of this study was the belief that hepatitis B is caused by curses. An earlier
35 study has shown that people attach superstitious beliefs to hepatitis B in Ghana.³⁴ Also, a
36 study conducted by Adjei et al. entitled “hepatitis B infection among perturient in Peri-Urban
37 Ghana” found that 86% ($n=168$) of participants linked the cause of hepatitis B to curses. This
38 association is unsurprising given that some clinical manifestations of hepatitis B, including
39 swollen abdomen and feet, are analogous to the outcomes of a curse in Ghanaian culture. In
40 Ghana, people are particularly cautious about handling items perceived to be cursed as not
41 handling them can help to avoid possible transfer of the consequences.

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45 In addition to documenting beliefs about hepatitis B that contribute to stigmatisation, we also
46 explored manifestations of hepatitis B stigma. One manifestation was avoidance. This finding
47 is consistent with other studies.^{55 57} For example, in a study conducted in Japan with a sample
48 of the working population, Eguchi and Wada⁵⁵ found that 32.1% of their study participants
49 avoided physical contact with colleagues after learning their HBV positive status. Similarly,
50 in an Iranian study, patients with hepatitis B reported believing that saliva is a source of
51 hepatitis B infection and therefore avoiding body contact with close relations including
52 kissing.⁵⁹

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3 In our study, we also found that stigma manifests as isolation and physical distance. Our
4 finding that students were isolated from their counterparts in school dormitories because of
5 their hepatitis B status is similar to a finding from a study in China where a university student
6 with hepatitis B was put in a single room instead of a shared dormitory.⁵⁸ In another
7 somewhat earlier study by Yang and Wu,⁶⁵ the findings showed that some universities and
8 kindergartens in China refused to admit prospective students who were hepatitis B positive.
9

10
11 Our study also looked specifically at hepatitis B stigma in healthcare settings. The findings
12 showed that stigmatisation took form as excessive cautiousness, task-shifting and procedure
13 avoidance, breaches of confidentiality, and silence by HCPs. Perhaps inadequate knowledge
14 and fear of acquisition of HBV among the HCPs led to the excessive cautiousness and fear.
15 This has been previously document by Yu and colleagues⁶⁶ in China. Similarly, Wada et al.³⁸,
16 in their study conducted in Japan, reported that some nurses were also reluctant to care for
17 PWHB due to a perceived risk of infection. In another study conducted in Iran with hepatitis
18 B patients by Dehkordi and others³⁹, nurses and doctors were reported to be hesitant caring
19 for PWHB after realising they have hepatitis B.
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23 Our findings have important practical implications. First, the findings provide important
24 insight on how to go about reducing hepatitis B stigma. Given the prevalence of incorrect
25 knowledge, as reflect in the beliefs about hepatitis B, we recommend public awareness
26 campaigns that emphasize hepatitis B transmission routes. Also, given the manifestations of
27 the stigma in the healthcare settings, we feel that a continuing professional development
28 programme on the epidemiology of hepatitis B is called as this can enhance their knowledge
29 in parallel to public awareness campaigns. Additionally, we recommend efforts to increase
30 health literacy on hepatitis B prevention measures, including vaccination, as this may
31 increase HCPs confidence when caring for PWHB. If developed based on both theory and
32 evidence and in collaboration with target populations, these interventions have the potential
33 to effectively reduce hepatitis B stigma in Ghana⁶⁷
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37 The findings of this study should be viewed in light of a few limitations. First, given the
38 qualitative nature of the study, it is important to be cautious in generalising these findings.
39 We therefore recommend following this study with a quantitative study that can quantify the
40 extent to which hepatitis stigma is present in Ghana. Second, given that participants,
41 particularly PWHB, were asked to retrospectively recall experiences, there is potential for
42 recall bias in this study. We, however, sought to reduce this by asking follow-up questions to
43 confirm or verify participants' experiences.
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47 **Conclusion**

48
49 This study gives insight about beliefs contributing to hepatitis B stigma in Ghana and its
50 manifestations. We found that beliefs that hepatitis B is highly contagious, very severe, and
51 caused by a curse are present and contribute to the stigmatisation of PWHB in Ghana.
52 Hepatitis B stigmatisation manifested as avoidance, isolation, and physical distance. In the
53 healthcare settings, excessive cautiousness, task-shifting, procedure avoidance, breaches of
54 confidentiality, and silence by HCPs were also found. We therefore recommend interventions
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3 that seek to alter the beliefs contributing to hepatitis B stigma in Ghana, starting with efforts
4 that correct knowledge deficits.
5

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10

11 **Abbreviation**

12 HBV- Hepatitis B Virus; PWHB- People with Hepatitis B; HCPs – Healthcare Providers; IDI
13 – In-depth Interviews; FGD – Focus Group Discussions
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18
19

20
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23

24
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26 study. Interview guide was designed by CAA and SES. Data analysis was done by CAA and
27 SES. Manuscript was critically reviewed by SES, FN, RACR. All authors read and approved
28 the manuscript.
29

30
31 **Competing interests:** The authors declare no conflict of interest in this study.

32 **Consent for publication:** Not applicable
33

34 **Ethical Approval**

35 Ethical clearance was obtained from Institutional Review Board of Korle-Bu Teaching
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37 management of the data collection sites, and informed consent (written) was obtained from
38 the participants.
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41 **References**

- 42
43
44
45
46 1. Schweitzer A, Horn J, Mikolajczyk RT, *et al.* Estimations of worldwide prevalence of
47 chronic hepatitis B virus infection: A systematic review of data published between
48 1965 and 2013. *Lancet* 2015;**386**:1546–55. doi:10.1016/S0140-6736(15)61412-X
49
50
51 2. WHO. Hepatitis B Fact Sheet. 2018a. [Retrieved from:
52 <http://www.who.int/mediacentre/factsheets/fs204/en/>. Available on February 06,
53 2018]
54
55
56
57

- 1
2
3 5. Ofori-Asenso R, Agyeman AA. Hepatitis B in Ghana: a systematic review & meta-analysis of prevalence studies (1995-2015). *BMC Infect Dis* 2016;**16**:130. doi:10.1186/s12879-016-1467-5
- 4
5
6
7
8 4. Musa BM, Bussell S, Borodo MM, *et al.* Prevalence of hepatitis B virus infection in Nigeria, 2000-2013: a systematic review and meta-analysis. *Niger J clin Pr* 2015;**18**:163–72. doi:10.4103/1119-3077.151035
- 9
10
11
12
13 5. Kolou M, Katawa G, Salou M, *et al.* High Prevalence of Hepatitis B Virus Infection in the Age Range of 20-39 Years Old Individuals in Lome. 2015;:1–7. doi:10.2174/1874357901710011001
- 14
15
16
17
18 6. Bigna JJ, Amougou MA, Asangbeh SL, *et al.* Seroprevalence of hepatitis B virus infection in Cameroon : a systematic review and meta-analysis. 2017;:1–12. doi:10.1136/bmjopen-2016-015298
- 19
20
21
22
23 7. Rufai T, Mutocheluh M, Kwarteng K, *et al.* The prevalence of hepatitis B virus E antigen among Ghanaian blood donors. *Pan Afr Med J* 2014;**17**:53. doi:10.11604/pamj.2014.17.53.3390
- 24
25
26
27
28 8. Mutocheluh M, Owusu M, Kwofie TB, *et al.* Risk factors associated with hepatitis B exposure and the reliability of five rapid kits commonly used for screening blood donors in Ghana. *BMC Res Notes* 2014;**7**:1–8. doi:10.1186/1756-0500-7-8739.
- 29
30
31
32 9. Sagoe KWC, Agyei AA, Ziga F, Lartey M, Adiku TK, Seshi M, Arens MQ, Mingle J A A. Prevalence and Impact of Hepatitis B and C Virus Co-Infections in Antiretroviral Treatment Naive Patients with HIV Infection at a Major Treatment Center in Ghana. *Journal of Medical Virology* 2012; **84**: 6-10
- 33
34
35
36
37 10. Adjei AA, Armah HB, Gbagbo F, *et al.* Correlates of HIV, HBV, HCV and syphilis infections among prison inmates and officers in Ghana: A national multicenter study. *BMC Infect Dis* 2008;**8**:1–12. doi:10.1186/1471-2334-8-33
- 38
39
40
41
42 11. Candotti D, Danso K, Allain J-P. Maternofetal transmission of hepatitis B virus genotype E in Ghana, west Africa. *J Gen Virol* 2007;**88**:2686–95. doi:10.1099/vir.0.83102-0
- 43
44
45
46 12. Cho Y, Bonsu G, Akoto-Ampaw A, *et al.* The prevalence and risk factors for hepatitis B surface Ag positivity in pregnant women in eastern region of Ghana. *Gut Liver* 2012;**6**:235–40. doi:10.5009/gnl.2012.6.2.235
- 47
48
49
50
51 13. Trépo C, Chan HLY, Lok A. Hepatitis B virus infection. *Lancet* 2014;**6736**:1–11. doi:10.1016/S0140-6736(14)60220-8
- 52
53
54
55 14. Giles-Vernick T, Hejoaka F, Sanou A, Shimakawa Y, Bamba I, Traoré A. Barriers to
- 56
57
58
59
60

- 1
2
3 Linkage to Care for Hepatitis B Virus Infection: A Qualitative Analysis in Burkina
4 Faso, West Africa. *Am J Trop Med Hyg* 2016;**95**:1368–75. doi:10.4269/ajtmh.16-
5 0398
6
7
8 15. Lemoine M, Eholié S, Lacombe K. Reducing the neglected burden of viral hepatitis
9 in Africa: Strategies for a global approach. *J Hepatol* 2015;**62**:469–76.
10 doi:10.1016/j.jhep.2014.10.008
11
12 16. Nwokediuko SC. Chronic Hepatitis B : Management Challenges in Resource-Poor
13 Coun- tries. 2011;**11**:786–93. doi:10.5812/kowsar.1735143X.757
14
15 17. Butt G, Paterson BL, McGuinness LK. Living with the stigma of hepatitis C. *West J*
16 *Nurs Res* 2008;**30**:204–21. doi:10.1177/0193945907302771
17
18 18. Sandelowski, M., Lambe, C., & Barroso, J. (2004). Stigma in HIV-Positive Women.
19 *J Nurs Scholarsh.*, 2004;36 (2):122-8
20
21
22 19. Stutterheim SE, Bos AER, Shiripinda I, *et al.* HIV-related stigma in African and
23 Afro-Caribbean communities in the Netherlands : Manifestations , consequences , and
24 coping. *Psychol Health* 2012;**27**:1–32. doi:10.1080/08870446.2011.585426
25
26
27 20. Colombini M, Mutemwa R, Kivunaga J, *et al.* Experiences of stigma among women
28 living with HIV attending sexual and reproductive health services in Kenya : a
29 qualitative study. 2014:1–9.
30
31
32 21. Courtwright A. Tuberculosis and Stigmatization : Pathways and Interventions.
33 ;**125**:34–42.
34
35
36 22. Miller C, Huston J, Samu L, *et al.* ‘ It makes the patient ’ s spirit weaker ’ :
37 tuberculosis
38 stigma and gender interaction in Dar es Salaam , Tanzania. 2017;**21**:42–9.
39
40
41 23. Cotler SJ, Cotler S, Xie H, *et al.* Characterizing hepatitis B stigma in Chinese
42 immigrants. *J Viral Hepat* 2012;**19**:147–52. doi:10.1111/j.1365-2893.2011.01462.x
43
44
45 24. Ellard, J. & Wallace J. (2013). Stigma and discrimination and hepatitis B: A review
46 of current research. *ARCSHS Monographs Series*, 93
47
48
49 25. Ng CJ, Low WY, Wong LP, *et al.* Uncovering the experiences and needs of patients
50 with chronic hepatitis B infection at diagnosis: a qualitative study. *Asia Pac J Public*
51 *Health* 2013;**25**:32–40. doi:10.1177/1010539511413258
52
53
54 26. Wu H, Yim C, Chan A, *et al.* Sociocultural factors that potentially affect the
55 institution
56
57
58
59
60

- of prevention and treatment strategies for hepatitis B in Chinese Canadians. *Can J Gastroenterol* 2009;**23**:31–6.
27. Alizadeh a HM, Ranjbar M, Yadollahzadeh M. Patient concerns regarding chronic hepatitis B and C infection. 2008;**14**:1142–8.
28. Guirgis M, Nusair F, Bu YM, *et al*. Barriers faced by migrants in accessing healthcare for viral hepatitis infection. *Intern Med J* 2012;**42**:491–6. doi:10.1111/j.1445-5994.2011.02647.x
29. WHO. “My untold story”- a hepatitis B patient in Ghana shares his experience. 2018b. [Retrieved from: http://www.who.int/hepatitis/news-events/ghana-pr-an_untold_story/en/. Available on February 20, 2018]
30. Pescosolido BA, Martin JK. Stigma Complex. *Annu. Rev. Sociol.*, 2015; **41**: 87–116.
31. Link B, Phelan J, Wheaton B, *et al*. Labeling and Stigma. *A Handb Study Ment Heal Soc Context Theor Syst* 1999;**367**:171–99. doi:10.1016/j.socscimed.2013.07.035.Stigma
32. Li D, Tang T, Patterson M, *et al*. The impact of hepatitis B knowledge and stigma on screening in Canadian Chinese persons. 2012;**26**:597–602.
33. Rafique I, Saqib MAN, Siddiqui S, *et al*. Experiences of stigma among hepatitis B and C patients in Rawalpindi and Islamabad, Pakistan/Expériences de stigmatisation chez des patients atteints d’hépatite B et C à Rawalpindi et Islamabad (Pakistan). *East Mediterr Heal J* 2014;**20**:796.
34. Adjei CA, Naab F, Donkor ES. Beyond the diagnosis: a qualitative exploration of the experiences of persons with hepatitis B in the Accra Metropolis, Ghana. *BMJ Open* 2017;**7**:e017665. doi:10.1136/bmjopen-2017-017665
35. Yoo GJ, Fang T, Zola J, *et al*. Destigmatizing hepatitis B in the Asian American community: Lessons learned from the San Francisco Hep B free campaign. *J Cancer Educ* 2012;**27**:138–44. doi:10.1007/s13187-011-0252-9
36. Huang J, Guan ML, Balch J, *et al*. Survey of hepatitis B knowledge and stigma among chronically infected patients and uninfected persons in Beijing, China. *Liver Int* 2016;**36**:1595–603. doi:10.1111/liv.13168

- 1
2
3 37. Carabez RM, Swanner JA, Yoo GJ, *et al.* Knowledge and fears among Asian
4 Americans chronically infected with hepatitis B. *J Cancer Educ* 2014;**29**:522–8.
5 doi:10.1007/s13187-013-0585-7
6
7 38. Wada K, Smith DR, Ishimaru T. Reluctance to care for patients with HIV or
8 hepatitis B / C in Japan. *BMC Pregnancy Childbirth* 2016;**16**:1–6.
9 doi:10.1186/s12884-016-0822-2
10
11 39. Dehkordi AH, Mohammadi N, NikbakhatNasrabadi A. Hepatitis-related stigma in
12 chronic patients: A qualitative study. *Appl Nurs Res* 2016;**29**:206–10.
13 doi:10.1016/j.apnr.2015.04.010
14
15 40. Lee H, Fawcett J, Yang JH, *et al.* Correlates of Hepatitis B Virus Health-Related
16 Behaviors of Korean Americans : A Situation-Specific Nursing Theory. 2012;:315–
17 22. doi:10.1111/j.1547-5069.2012.01468.x
18
19 41. Shi J, Chyun D a., Sun Z, *et al.* Assessing the stigma toward chronic carriers of
20 hepatitis B virus: development and validation of a Chinese college students' stigma
21 scale. *J Appl Soc Psychol* 2013;**43**:E46–55. doi:10.1111/jasp.12040
22
23 42. Mohamed R, Ng CJ, Tong WT, *et al.* Knowledge, attitudes and practices among
24 people with chronic hepatitis B attending a hepatology clinic in Malaysia: a cross
25 sectional study. *BMC Public Health* 2012;**12**:601. doi:10.1186/1471-2458-12-601
26
27 43. Wallace J, McNally S, Richmond J, *et al.* Managing chronic hepatitis B: A
28 qualitative study exploring the perspectives of people living with chronic hepatitis B in
29 Australia. *BMC Res Notes* 2011;**4**:45. doi:10.1186/1756-0500-4-45
30
31
32 44. Spearman CW, Afihene M, Ally R, *et al.* Hepatitis B in sub-Saharan Africa:
33 strategies to achieve the 2030 elimination targets. *Lancet Gastroenterol Hepatol*
34 2017;**2**:2121. doi:10.1016/S2468-1253(17)30295-9
35
36
37 45. Labaree RV. Organising your Social sciences Research Paper: Types of
38 Research designs. 2009.[Retrieved from:
39 <http://libguides.usc.edu/writingguide/researchdesigns>. Availabe on January 25, 2018]
40
41 46. Ghana Statistical Service. Ghana Health Service (GHS), and ICF Macro.
42 Ghana Demographic and Health Survey 2008, Calverton, Maryland, USA: GSS,
43 GHS, and Macro International. 2009
44
45 47. Ghana Statistical Service. 2010 population projected by sex, 2010-2016. 2016.
46 Retrieved from: http://www.statsghana.gov.gh/pop_stats.html, Accessed on May 24,
47 2018]
48
49 48. Ministry of Health. Category: Ministry agencies. 2018. [Retrieved from:
50 <http://www.moh.gov.gh/category/ministry-agencies/>, Accessed on January 01, 2017]
51
52 49. Carter N, Bryant-Lukosius D, DiCenso A, *et al.* The Use of Triangulation in
53 Qualitative Research. *Oncol Nurs Forum* 2014;**41**:545–7. doi:10.1188/14.ONF.545-
54 547
55
56
57
58
59
60

- 1
2
3
4 50. Etikan I, Musa SA, Alkassim RS. Comparison of Convenience Sampling and
5 Purposive Sampling. 2016;**5**:1–4. doi:10.11648/j.ajtas.20160501.1
6
7 51. Palinkas L a, Horwitz SM, Green C a, *et al.* Purposeful Sampling for Qualitative
8 Data Collection and Analysis in Mixed Method Implementation Research. *Adm Policy*
9 *Ment Heal* 2015;**42**:533–44. doi:10.1007/s10488-013-0528-y.Purposeful
10
11
12 52. Wellings K, Branigan P, Mitchell K. Discomfort, discord and discontinuity as data:
13 Using focus groups to research sensitive topics. *Cult Heal Sex* 2000;**2**:255–67.
14 doi:10.1080/136910500422241
15
16 53. Polit DF, Beck CT. Nursing research: Principles and methods (8TH
17 Edition). 2014. Lippincot William & Wilkins.
18
19 54. Graneheim UH, Lundman B. Qualitative content analysis in nursing research:
20 Concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*
21 2004;**24**:105–12. doi:10.1016/j.nedt.2003.10.001
22
23 55. Eguchi H, Wada K. Knowledge of HBV and HCV and Individuals' Attitudes
24 Toward HBV- and HCV-Infected Colleagues: A National Cross-Sectional Study
25 among a Working Population in Japan. *PLoS One* 2013;**8**:1–7.
26 doi:10.1371/journal.pone.0076921
27
28 56. Dahl TFM, Cowie BC, Biggs B, *et al.* Health literacy in patients with chronic
29 hepatitis
30 B attending a tertiary hospital in Melbourne : a questionnaire based survey. 2014;:1–
31 9.
32
33 57. Dam L, Cheng A, Tran P, *et al.* Hepatitis B stigma and knowledge among
34 Vietnamese in Ho Chi Minh City and Chicago. *Can J Gastroenterol Hepatol*
35 2016;**2016**. doi:10.1155/2016/1910292
36
37 58. Kan Q, Wen J, Xue R. Discrimination against people with hepatitis B in China.
38 *Lancet* 2015;**386**:245–6. doi:10.1016/S0140-6736(15)61276-4
39
40 59. Valizadeh L, Zamanzadeh V, Bayani M, *et al.* The Social Stigma Experience in
41 Patients With Hepatitis B Infection. *Gastroenterol Nurs* 2017;**40**:143–50.
42 doi:10.1097/SGA.0000000000000223
43
44 60. Ochu CL, Beynon CM. Hepatitis B vaccination coverage, knowledge and
45 sociodemographic determinants of uptake in high risk public safety workers in
46 Kaduna State, Nigeria: A cross sectional survey. *BMJ Open* 2017;**7**:1–10.
47 doi:10.1136/bmjopen-2017-015845
48
49 61. Schillie S, Vellozzi C, Reingold A, Harris A, Haber P, Ward JW,
50 Nelson NP. Prevention of hepatitis B virus infection in the United States:
51 Recommendations of the Advisory Committee on Immunisation Practices. MMWR
52 Report. 2018. [Retrieved from
53
54
55
56
57
58
59
60

<https://www.cdc.gov/mmwr/volumes/67/rr/rr6701a1.htm>. Available on February 20, 2018]

62. Hajarizadeh B, Wallace J, Richmond J, *et al*. Hepatitis B knowledge and associated factors among people with chronic hepatitis B. *Aust N Z J Public Health* 2015;**39**:563–8. doi:10.1111/1753-6405.12378
63. Upadhyaya N, Chang R, Davis C, *et al*. Chronic hepatitis B: Perceptions in Asian American communities and diagnosis and management practices among primary care physicians. *Postgrad Med* 2010;**122**:165–75. doi:10.3810/pgm.2010.09.2213
64. WHO. Guidelines for the prevention, care and treatment of persons with chronic hepatitis B infection. 2015;:166.
65. Yang T, Wu MC. Discrimination against hepatitis B carriers in China. *Lancet* 2011;**378**:1059. doi:10.1016/S0140-6736(11)61460-8
66. Yu L, Wang J, Zhu D, *et al*. Hepatitis B-related knowledge and vaccination in association with discrimination against hepatitis B in rural China. *Hum Vaccines Immunother* 2016;**12**:70–6. doi:10.1080/21645515.2015.1069932
67. Eldredge LKB, Markham CM, Ruiters RAC, Fernández MA, Kok G, Parcel GS. *Planning Health Promotion Programmes: An Intervention Mapping Approach (4th Edition)*. 2016. Jossey-Bass

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			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

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

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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BMJ Open

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

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3 **The challenge of stigma among people with chronic Hepatitis B in Ghana: a qualitative**
4 **study**
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43 **ABSTRACT**

44 **Objective:** This study explored the perspectives of people with chronic Hepatitis B and
45 healthcare providers on the beliefs contributing to Hepatitis B stigma in Northern and Southern
46 Ghana and the ways in which Hepatitis B stigma manifests.
47

48 **Design:** We used an exploratory qualitative design with a purposive sampling technique. Face-
49 to-face interviews and focus group discussions were conducted. Data were processed using
50 QSR Nvivo version 10.0 and analysed using inductive thematic analysis.
51

52 **Settings:** Participants were recruited from one tertiary and one regional hospital in Ghana
53 between February and November, 2017.
54

55 **Participants:** Overall, 18 people with chronic Hepatitis B and 47 healthcare providers (primary
56 care physicians, nurses, and midwives) between the ages of 21 and 57 years participated in the
57 study.
58

59 **Results:** The findings of the study showed that people with chronic Hepatitis B are faced with
60 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 affected² as evidenced by the high HBV prevalence in the region.³⁻⁶

Within the Ghanaian context, several studies have estimated Hepatitis B prevalence above 8%.³⁷⁻¹² In fact, the most recent prevalence estimate of Hepatitis B in Ghana is 12.3%.³ HBV transmission occurs through several means.¹¹³ 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

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3 such as the high cost of testing and treatment, poor referral systems, a lack of HBV management
4 guidelines, and inadequate infrastructure for screening contribute to the high prevalence of
5 Hepatitis B in developing countries, including Ghana.¹⁴⁻¹⁶
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8 Generally, diseases with some risk of transmission are associated with stigma.^{17 18} This is well
9 reported for conditions such as tuberculosis, HIV, and mental illnesses.¹⁹⁻²² Similarly, people
10 with chronic Hepatitis B (PWHB) are likely to be stigmatised.²³⁻²⁹ Goffman³⁰ in his seminal
11 work described stigmatisation as a socially and culturally constituted process whereby a person
12 is first labelled as different and then devalued, leading to status loss and discrimination. Link
13 and Phelan³¹ also outlined three main motivations for stigmatisation namely: exploitation and
14 domination (keeping people down), enforcement of social norms (keeping people in), and
15 avoidance of diseases (keeping people away). Exploitation and domination occur when a group
16 dominate or exploit another by virtue of their wealth, power and high social status. On the other
17 hand, enforcement of social norm centres on written and unwritten rules that people are
18 expected to follow and violaters of these norms suffer the consequences.³¹ However, because
19 Hepatitis B is an infectious disease, disease avoidance as a motivation for stigmatisation is
20 likely. This is supported by evidence from Canada and Pakistan showing that PWHB
21 experience diverse degrees of stigma because of the perceived infectiousness of HBV.³²⁻³³
22 Stigmatisation may also be motivated by a desire to enforce social norms as Hepatitis B has
23 been reported to be considered the consequence of promiscuous behaviour.^{29 34 35} In additon,
24 ignorance about HBV routes of transmission is documented to contributes to Hepatitis B
25 stigma.³⁶
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34 The stigmatisation of PWHB manifests in many ways. Previous studies conducted outside of
35 Ghana have reported social exclusion, problems with close relations including friends and
36 families, and loss of employment as some of the ways in which Hepatitis B stigma presents.³³
37 ³⁵⁻³⁷ Hepatitis B stigmatisation also occurs across a number of settings and contexts, including
38 health care settings.^{38 39} For example, Wada and colleagues³⁸ found that some healthcare
39 providers in Japan were reluctant to care for patients with chronic Hepatitis B due to fear of
40 infection.
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44 The stigmatisation of PWHB has many consequences. It has been found to create an
45 environment of secrecy and denial, can lead to depression, and can be a barrier to health care
46 seeking, including screening and treatment.^{28 32 39-41} Additionally, fear of being stigmatised,
47 rejected, and discriminated against has been found to motivate PWHB to conceal their positive
48 status from family and friends,^{25 39 42 43} and non-disclosure of one's HBV status can be a barrier
49 to preventing transmission to others.⁴⁴ Further, stigmatisation can serve to deter people at risk
50 for HBV infection from being tested, obtaining treatment when eligible, and from seeking
51 assistance for risk reduction.^{28 32 41}
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56 Given the high prevalence of Hepatitis B in Ghana,³ and the paucity of evidence on Hepatitis
57 B stigma in Ghana, this study sought to explore the perspectives of PWHB and HCPs on the
58 beliefs contributing to Hepatitis B stigma in Northern and Southern Ghana and the ways in
59 which Hepatitis B stigma manifests. Understanding this phenomenon is important as it can
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3 inform the design of effective Hepatitis B and stigma prevention interventions and policies in
4 Ghana and beyond.
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7 **METHODS**

8 **Study Design**

9
10 An exploratory qualitative design was used to explore the perspectives of PWHB and HCPs on
11 Hepatitis B stigma in Ghana. This design was deemed best suited for this study because there
12 is very limited documented evidence on Hepatitis B stigma in Ghana.⁴⁵ Ethical approval was
13 given by the Korle-Bu Institutional Review Board (Approval number KBTH-IRB
14 00092/2016).
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17 **Study Setting**

18
19 The study was conducted in two public health facilities in Ghana. Ghana is a tropical country
20 on the west coast of Africa.⁴⁶ According to the most recent census, the population of Ghana
21 was about 28, 308, 301 in 2016.⁴⁷ There are ten administrative regions in the country. Each of
22 the regions has a regional hospital which serves as a referral centre for the district hospitals.
23 Also, the country has three main teaching hospitals.⁴⁸ A special clinic for patients with liver
24 conditions, including Hepatitis B, are run at the tertiary hospitals whereas PWHB are mostly
25 treated as out-patient cases in regional hospitals. One tertiary hospital in the south and one
26 regional hospital in the North were selected for the study. In most Ghanaian societies, people
27 attach different beliefs to the cause of their illness depending on their religious affiliation. For
28 example, Christians and Moslems recognise God as the one who controls life events and also
29 has the power to deliver people from bad situations including illnesses. On the other hand,
30 those with traditional beliefs also attribute the cause of unusual event including illness to
31 consequences of a sin against the gods.
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37 **Study Population**

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39 We recruited PWHB and HCPs including primary physicians, nurses, and midwives in both
40 Northern and Southern Ghana for the purposes of data source triangulation. Ensuring
41 triangulation was imperative to understanding the Hepatitis B stigma comprehensively and to
42 further validating information obtained from the participants.⁴⁹ Inclusion of HCPs was deemed
43 appropriate as they play an important role in the provision of care to PWHB. Also, some of the
44 manifestations of stigma occur in the clinical setting and therefore we believed that they were
45 in a better position to share those experiences with us.
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48 **Participant Eligibility**

49 **Inclusion Criteria**

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51 PWHB were included in the study if they were (1) 18 years or older, and (2) had tested Hepatitis
52 B surface antigen (HBsAg) positive at least 6 months prior to recruitment. The inclusion
53 criterion for HCPs was (1) having cared for patients with Hepatitis B in a healthcare setting.
54

55 **Exclusion Criteria**

56
57 PWHB who were in the terminal stage of the disease and had less energy to go through the
58 interview session were excluded. However, only one person in the terminal stage of the disease
59 was seen in the tertiary hospital but was not recruited because he was in a state of dyspnoea
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3 (breathlessness). Also, HCPs who had less than three months working experience in a
4 department where services are provided for PWHB were excluded as these HCPs might not
5 have enough experience with Hepatitis B.
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8 **Sampling Method and Data Collection Procedure**

9
10 A purposeful sampling technique was employed.^{50 51} First, posters with details of the study,
11 including information about the purpose of the study, assurance of the voluntary nature of the
12 study, as well as the procedure for registration, were advertised in the selected health facilities.
13 In addition, PWHB and HCPs were also recruited directly through nurses at the health facilities.
14 PWHB recruited through the advertisement were 6 and the remaining 12 were recruited through
15 nurses in the hospitals. On the other hand, 10 HCPs were recruited through advertisement and
16 37 of the HCPs were recruited through nurses in the hospitals. Overall, 16 participants were
17 recruited through the advertisements and 49 through nurses. Two PWHB refused to participate.
18 One cited time constraints as the reason and the other declined to provide a reason. Another 5
19 HCPs did not honour the invitation as a result of an emergency call at work or conflicting
20 schedule with other unplanned social events. PWHB participated in semi-structured in-depth
21 interviews. HCPs were either interviewed or participated in a focus group discussion (FGD).
22 The combination of interviews and FGD for HCP assisted in understanding and describing the
23 phenomenon comprehensively in terms of depth and breadth and further ensured the
24 trustworthiness of the findings (Lambert & Loiselle, 2008). However, given the sensitive nature
25 of the topic and the extent to which responses to the study questions could be quite personal
26 for PWHB, PWHB were not recruited for FGDs. Interviews were deemed more appropriate.⁵²
27 The interviews and FGD were conducted by the first author (CAA) who is a PhD student with
28 a good background in qualitative data collection including interviews and FGD. He is also fluent
29 in English and the local Ghanaian language (Twi) but all interviews and FGD were done in
30 English. Two days before the interview/FGD, participants were contacted by telephone to
31 remind them of the appointment. The interviews/FGDs were conducted mostly in the homes
32 of those with chronic Hepatitis B (under trees) and the workplace of HCPs (nurses' stations
33 and physician's consulting rooms). The informed consent form was signed by all participants
34 following an explanation of the purpose of the study and explicit mention of the confidential
35 and voluntary nature of their participation. In addition, permission was sought from participants
36 to record the interview/FGD. Field notes were taken during the interviews and the FGDs.
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47 Data were collected between February and November 2017. In total, 18 in-depth interviews
48 were conducted with PWHB and 15 in-depth interviews with HCPs. Additionally, 4 FGD with
49 a composition of 8 HCPs in each group were conducted. The interviews involving PWHB and
50 HCPs lasted between 45 minutes and 1 hour whereas the FGDs with HCPs lasted
51 approximately 1 hour and 15 minutes. Data saturation was reached after the interview of the
52 14th PWHB and 12th HCP.⁵³
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56 **Research Instrument**

57 The interview and FGD were guided by a semi-structured protocol with the flexibility to probe.
58 The protocol was developed based on empirical literature on Hepatitis B stigma⁵⁴ and then
59 reviewed by an expert in stigma (SS). Subsequently, the interview protocol was piloted with
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3 two PWHB and two HCPs. Topics explored during the interviews with PWHB include (1)
4 participants experiences being treated poorly or differently because of their HBV sero-
5 positivity and the settings in which those experiences took place (2) perceived reasons for being
6 treated poorly or differently (3) the impact of those experiences. Topics explored in the
7 interviews and FGDs with HCPs were (1) perceptions about Hepatitis B, (2) the extent to which
8 they have provided care to someone with Hepatitis B and, their reactions (3) possible reasons
9 for negative reactions to PWHB. A detailed interview protocol can be found in the
10 supplementary material 1.
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15 **Data Analysis**

16 Data were processed with QSR Nvivo version 10.0 and analysed using inductive thematic
17 analysis.⁵⁵ The first author (CAA) played and listened to the audio recordings and transcribed
18 verbatim. The first transcribed data were coded by two of the authors (CAA and SS) followed
19 by discussions on the individual codes, categories, and themes generated. At the end, a
20 consensus was reached on the codes, and the main themes and sub-themes were documented.
21 Preliminary findings were checked with two representatives of the study population to confirm
22 if the findings were in lines with their views and experiences. Two main themes and eight sub-
23 themes emerged from the data (summary presented in table 1).
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28 **Patient/Public Involvement**

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

38 **Demographic Characteristics**

39 We recruited, in total, 18 PWHB and 47 HCPs, of which 8 were physicians, 34 were nurses,
40 and 5 were midwives. PWHB were between 21 and 57 years of age and the HCPs were between
41 23 and 49 years of age. PWHB had lived with the infection between 1 and 7 years and had been
42 diagnosed through one of the following means: self-initiated, physician initiated, during
43 outreach screening services, and as a result of hospital protocol for pregnant women. The HCPs
44 had practised medicine, nursing, or midwifery between 1 and 20 years. Detailed socio-
45 demographic data for PWHB and HCPs are presented in table 2 and table 3 respectively.
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51 **Beliefs About Hepatitis B**

52 PWHB and HCP reported that, in Ghana, Hepatitis B is considered highly contagious and very
53 severe. Additionally, it is sometimes associated with curses. These themes are described in
54 detail below.
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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 2¹)

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

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3 easy identification and notification. Also, HCPs reported treating PWHB differently because
4 they fear possible infection. Some of the reactions from HCP are as follows,
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7 *“I am a midwife and in the ward, we have given those with Hepatitis B names. We call them*
8 *candidates. When we identify you as a candidate, most midwives don’t want to touch such a*
9 *person. Even we ignore their money because we believe that where she kept the money sweat*
10 *could get to it and therefore we don’t like it.”* (HCP, North-FGD 13)
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14 Fear of infection on the part of HCPs was also said to result in patients with chronic Hepatitis
15 B being neglected by some HCPs.
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18 *“We had one Hepatitis B case that came in a coma state and if you look at the severity of the*
19 *condition, most of the staff were not willing to provide any service for the patient. The patient*
20 *was restless and ended up losing his life after three days. After he died, nobody even wanted*
21 *to go closer to his dead body because we were afraid that we could be infected.”* (HCP, South-
22 IDI 10)
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25 **Hepatitis B as very severe**

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27 Participants also indicated that many people think Hepatitis B is not only easily transmittable
28 but very severe. Hepatitis B was claimed to be seen as a condition with poor prognosis which
29 eventually leads to death. One participant with chronic Hepatitis B shared her view,
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32 *“Everyone is afraid of the Hepatitis B virus. Since it is known that it kills, no one wants to have*
33 *anything to do with people who have it. Many people are aware of HIV but because it is well*
34 *publicised that Hepatitis B is more deadly than HIV, people are terrified when getting closer*
35 *to those who are known to have Hepatitis B.”* (PWHB, South-IDI 18).
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39 Another HCP said, *“People who are aware of Hepatitis B know that it kills. They are very*
40 *cautious when they hear that someone has Hepatitis B.”* (HCP, South-IDI 2).
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44 Participants emphasized the severity by comparing Hepatitis B to HIV/AIDS as illustrated by
45 this quote: *“People say it is deadly, it kills faster than HIV/AIDS.”* (HCP, South-IDI 12)

46 A belief that was said to contribute to the perceived severity of Hepatitis B is the belief that
47 Hepatitis B is incurable.
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49 *“What scares us is the information that Hepatitis B has no cure. It therefore means that is*
50 *either you die with it or you live with it forever. HIV which is a popular disease seems to be*
51 *better than Hepatitis B because there are drugs to keep you alive when you get it.”* (PWHB,
52 North-IDI 14)
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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.

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“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,

“Hmmm! 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 from their peers in an effort to prevent possible transmission of the virus to other students. One HCP narrated an encounter she had with a man, whose son suffered this treatment in school,

“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,

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“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”

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3 *when they are handing over - sometimes it is very obvious that they are stigmatising the client.*”
4 (HCP, South- IDI 1)
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7 **Task-shifting and procedure avoidance**

8 The majority of the HCPs indicated that postponement of procedures and task shifting are
9 common when caring for PWHB. In some instances, HCPs failed to perform nursing
10 procedures but, rather, delayed care when the patient was identified as having chronic Hepatitis
11 B. This too was reported to occur because of the perceived contagiousness of Hepatitis B.
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15 *“When we see them [PWHB] at the critical stage, some vomiting blood and coughing out*
16 *blood, you will see some nurses postponing procedures because they think that they can be*
17 *infected.”* (HCP, North-FGD 5)
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20 Another participant said,

21 *“I ever sent a patient to the hospital. The intravenous line infiltrated and the nurses were*
22 *supposed to change it. I was amazed that no nurse was ready to do it. This nurse will say to the*
23 *other to go and do it. Another said let’s wait for the doctor and giggled. So I was getting afraid.*
24 *Is this person having HIV or what that no one seems interested working on him?”* (HCP, North-
25 FGD 23)
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29 A number of the participants indicated that some HCPs shift their tasks such that student nurses
30 have to perform them. A nurse recounted her experience during her formal clinical training,
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33 *“During our clinical placement, when cases like Hepatitis B are admitted, it was we, the*
34 *students, that the nurses used to send to go and manage those clients. In fact, they won’t let*
35 *you know the exact condition until you cannot do something. Even that, when one of them is*
36 *coming to help you, the gloves will be more than five. Even with that, she will still come and*
37 *stand and say, “hold this place”, “do that”. She will not do it. So, if they begin to do that and*
38 *you also take the patient’s folder and you see that it is Hepatitis B, then you advise yourself”*
39 (HCP, North - FGD 19)
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43 Another nurse said,

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

54 The final manifestations of stigma that were reported to occur in healthcare settings was
55 breaches of confidentiality. Participants reported that some HCPs indeed fail to maintain
56 confidentiality. According to some participants, it is common to receive information about
57 PWHB from a colleague in the various hospital wards and units.
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“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 colleagues³³ 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 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 transmission⁶¹ 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}

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3 Additionally, with the exception of Hepatitis B testing which is covered by the national health
4 insurance scheme when requested by physicians, Hepatitis B vaccination is offered at a fee.
5 The only national policy on Hepatitis B prevention in Ghana is the administration of Hepatitis
6 B pentavalent vaccine to newborns at the 6, 10, 14 weeks after birth.³⁴
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9 Another finding of this study was the belief that Hepatitis B is caused by curses. An earlier
10 study has shown that people attach superstitious beliefs to Hepatitis B in Ghana.³⁴ Also, a study
11 conducted by Adjei et al. entitled "Hepatitis B infection among perturient in Peri-Urban
12 Ghana" found that 86% ($n=168$) of participants linked the cause of Hepatitis B to curses. This
13 association is unsurprising given that some clinical manifestations of Hepatitis B, including
14 swollen abdomen and feet, are analogous to the outcomes of a curse in Ghanaian culture. In
15 Ghana, people are particularly cautious about handling items perceived to be cursed as not
16 handling them can help to avoid possible transfer of the consequences.
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20 In addition to documenting beliefs about Hepatitis B that contribute to stigmatisation, we also
21 explored manifestations of Hepatitis B stigma. One manifestation was avoidance. This finding
22 is consistent with other studies.^{55 57} For example, in a study conducted in Japan with a sample
23 of the working population, Eguchi and Wada⁵⁵ found that 32.1% of their study participants
24 avoided physical contact with colleagues after learning their HBV positive status. Similarly, in
25 an Iranian study, patients with Hepatitis B reported believing that saliva is a source of Hepatitis
26 B infection and therefore avoiding body contact with close relations including kissing.⁵⁹
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30 In our study, we also found that stigma manifests as social isolation. Our finding that students
31 were isolated from their counterparts in school dormitories because of their Hepatitis B status
32 is similar to a finding from a study in China where a university student with Hepatitis B was
33 put in a single room instead of a shared dormitory.⁵⁸ In another somewhat earlier study by Yang
34 and Wu,⁶⁵ the findings showed that some universities and kindergartens in China refused to
35 admit prospective students who were Hepatitis B positive.
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39 Our study also looked specifically at Hepatitis B stigma in healthcare settings. The findings
40 showed that stigmatisation took form as excessive cautiousness, task-shifting and procedure
41 avoidance, and breaches of confidentiality. Perhaps inadequate knowledge and fear of
42 acquisition of HBV among the HCPs led to the excessive cautiousness and fear. This has been
43 previously document by Yu and colleagues⁶⁶ in China. Similarly, Wada et al.³⁸, in their study
44 conducted in Japan, reported that some nurses were also reluctant to care for PWHB due to a
45 perceived risk of infection. In another study conducted in Iran with chronic Hepatitis B patients
46 by Dehkordi and others³⁹, nurses and doctors were reported to be hesitant caring for PWHB
47 after realising they have Hepatitis B.
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52 Our findings have important practical implications. First, the findings provide important insight
53 on how to go about reducing Hepatitis B stigma. Given the prevalence of incorrect knowledge,
54 as reflect in the beliefs about Hepatitis B, we recommend public awareness campaigns that
55 emphasize Hepatitis B transmission routes. Also, given the manifestations of the stigma in the
56 healthcare settings, we feel that a continuing professional development programme on the
57 aetiology of Hepatitis B is called as this can enhance HCPs knowledge in parallel to public
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3 awareness campaigns. Additionally, we recommend efforts to increase health literacy on
4 Hepatitis B prevention measures, including vaccination, as this may increase HCPs confidence
5 when caring for PWHB. If developed based on both theory and evidence and in collaboration
6 with target populations, these interventions have the potential to effectively reduce Hepatitis B
7 stigma in Ghana.⁶⁷ In addition, PWHB should be counsel on the relevance of using either
8 problem focused coping strategies such as seeking social support, affiliating with others with
9 same disease and emotion-focused strategies such as religious coping and positive reappraisal
10 as a way of building their resilience.^{19 68} Stigma reduction intervention such as psycho-
11 educational intervention which focuses on education, skill building, empowerment, and social
12 support can be explored in Ghana.⁶⁹
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17 The findings of this study should be viewed in light of a few limitations. Although this study
18 provided insight into the beliefs contributing to Hepatitis B stigma and the manifestations of
19 stigma in Ghana, we recommend confirming these results quantitatively in a large
20 representative sample of the Ghanaian population. Second, given that participants, particularly
21 PWHB had lived with the infection for a period between one and seven years, and were asked
22 to recall their experiences retrospectively, there was potential for recall bias. We, however,
23 sought to reduce this by asking follow-up questions to confirm or verify participants'
24 experiences. The third limitation of this study is the exclusion of PWHB who were in the
25 terminal stage of the disease. We therefore recognise that their experiences with stigma might
26 differ from our study participants.
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31 **Conclusion**

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33 This study gives insight about beliefs contributing to Hepatitis B stigma in Ghana and its
34 manifestations. We found that beliefs that Hepatitis B is highly contagious, very severe, and
35 caused by a curse are present and contribute to the stigmatisation of PWHB in Ghana. Hepatitis
36 B stigmatisation manifested as avoidance and social isolation. In the healthcare settings,
37 excessive cautiousness, task-shifting, procedure avoidance, and breaches of confidentiality
38 were also found. We therefore recommend interventions that seek to alter the beliefs
39 contributing to Hepatitis B stigma in Ghana, starting with efforts that correct knowledge
40 deficits.
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51 **Abbreviation**

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

57 No funding
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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.

References

1. Schweitzer A, Horn J, Mikolajczyk RT, *et al.* Estimations of worldwide prevalence of chronic hepatitis B virus infection: A systematic review of data published between 1965 and 2013. *Lancet* 2015;386:1546–55. doi:10.1016/S0140-6736(15)61412-X
2. WHO. Hepatitis B Fact Sheet. 2018a. [Retrieved from: <http://www.who.int/mediacentre/factsheets/fs204/en/>. Available on February 06, 2018]
3. Ofori-Asenso R, Agyeman AA. Hepatitis B in Ghana: a systematic review & meta-analysis of prevalence studies (1995-2015). *BMC Infect Dis* 2016;16:130. doi:10.1186/s12879-016-1467-5
4. Musa BM, Bussell S, Borodo MM, *et al.* Prevalence of hepatitis B virus infection in Nigeria, 2000-2013: a systematic review and meta-analysis. *Niger J clin Pr* 2015;18:163–72. doi:10.4103/1119-3077.151035
5. Kolou M, Katawa G, Salou M, *et al.* High Prevalence of Hepatitis B Virus Infection in the Age Range of 20-39 Years Old Individuals in Lome. 2015;:1–7. doi:10.2174/1874357901710011001
6. Bigna JJ, Amougou MA, Asangbeh SL, *et al.* Seroprevalence of hepatitis B virus infection in Cameroon : a systematic review and meta-analysis. 2017;:1–12. doi:10.1136/bmjopen-2016-015298

- 1
2
3 7. Rufai T, Mutocheluh M, Kwarteng K, *et al.* The prevalence of hepatitis B virus E
4 antigen among Ghanaian blood donors. *Pan Afr Med J* 2014;**17**:53.
5 doi:10.11604/pamj.2014.17.53.3390
6
7
- 8
9 8. Mutocheluh M, Owusu M, Kwofie TB, *et al.* Risk factors associated with hepatitis B
10 exposure and the reliability of five rapid kits commonly used for screening blood donors
11 in Ghana. *BMC Res Notes* 2014;**7**:1–8. doi:10.1186/1756-0500-7-8739.
12
- 13
14 9. Sagoe KWC, Agyei AA, Ziga F, Lartey M, Adiku TK, Seshi M, Arens MQ, Mingle J
15 A A. Prevalence and Impact of Hepatitis B and C Virus Co-Infections in Antiretroviral
16 Treatment Naive Patients with HIV Infection at a Major Treatment Center in Ghana.
17 *Journal of Medical Virology* 2012; **84**: 6-10
18
- 19
20 10. Adjei AA, Armah HB, Gbagbo F, *et al.* Correlates of HIV, HBV, HCV and syphilis
21 infections among prison inmates and officers in Ghana: A national multicenter study.
22 *BMC Infect Dis* 2008;**8**:1–12. doi:10.1186/1471-2334-8-33
23
- 24
25 11. Candotti D, Danso K, Allain J-P. Maternofetal transmission of hepatitis B virus
26 genotype E in Ghana, west Africa. *J Gen Virol* 2007;**88**:2686–95.
27 doi:10.1099/vir.0.83102-0
28
- 29
30 12. Cho Y, Bonsu G, Akoto-Ampaw A, *et al.* The prevalence and risk factors for
31 hepatitis B surface Ag positivity in pregnant women in eastern region of Ghana. *Gut*
32 *Liver* 2012;**6**:235–40. doi:10.5009/gnl.2012.6.2.235
33
- 34
35 13. Trépo C, Chan HLY, Lok A. Hepatitis B virus infection. *Lancet* 2014;**6736**:1–11.
36 doi:10.1016/S0140-6736(14)60220-8
37
- 38
39 14. Giles-Vernick T, Hejoaka F, Sanou A, Shimakawa Y, Bamba I, Traoré A. Barriers to
40 Linkage to Care for Hepatitis B Virus Infection: A Qualitative Analysis in Burkina
41 Faso, West Africa. *Am J Trop Med Hyg* 2016;**95**:1368–75. doi:10.4269/ajtmh.16-
42 0398
43
- 44
45 15. Lemoine M, Eholié S, Lacombe K. Reducing the neglected burden of viral hepatitis
46 in Africa: Strategies for a global approach. *J Hepatol* 2015;**62**:469–76.
47 doi:10.1016/j.jhep.2014.10.008
48
- 49
50 16. Nwokediuko SC. Chronic Hepatitis B : Management Challenges in Resource-Poor
51 Coun- tries. 2011;**11**:786–93. doi:10.5812/kowsar.1735143X.757
52
- 53
54 17. Butt G, Paterson BL, McGuinness LK. Living with the stigma of hepatitis C. *West J*
55 *Nurs Res* 2008;**30**:204–21. doi:10.1177/0193945907302771
56
- 57
58 18. Sandelowski, M., Lambe, C., & Barroso, J. (2004). Stigma in HIV-Positive Women.
59 *J Nurs Scholarsh.*, 2004;**36** (2):122-8
60

19. Stutterheim SE, Bos AER, Shiripinda I, *et al.* HIV-related stigma in African and Afro-Caribbean communities in the Netherlands : Manifestations , consequences , and coping. *Psychol Health* 2012;**27**:1–32. doi:10.1080/08870446.2011.585426
20. Colombini M, Mutemwa R, Kivunaga J, *et al.* Experiences of stigma among women living with HIV attending sexual and reproductive health services in Kenya : a qualitative study. 2014:1–9.
21. Courtwright A, Turner NA. Tuberculosis and Stigmatization :Pathways and Interventions. *Public Health Reports* 2010;**125**:34–42.
22. Miller C, Huston J, Samu L, *et al.* ‘ It makes the patient’s spirit weaker’: tuberculosis stigma and gender interaction in Dar es Salaam , Tanzania. 2017;**21**:42–9.
23. Cotler SJ, Cotler S, Xie H, *et al.* Characterizing hepatitis B stigma in Chinese immigrants. *J Viral Hepat* 2012;**19**:147–52. doi:10.1111/j.1365-2893.2011.01462.x
24. Ellard, J. & Wallace J. (2013). Stigma and discrimination and hepatitis B: A review of current research. *ARCSHS Monographs Series*, 93
25. Ng CJ, Low WY, Wong LP, *et al.* Uncovering the experiences and needs of patients with chronic hepatitis B infection at diagnosis: a qualitative study. *Asia Pac J Public Health* 2013;**25**:32–40. doi:10.1177/1010539511413258
26. Wu H, Yim C, Chan A, *et al.* Sociocultural factors that potentially affect the institution of prevention and treatment strategies for hepatitis B in Chinese Canadians. *Can J Gastroenterol* 2009;**23**:31–6.
27. Alizadeh a HM, Ranjbar M, Yadollahzadeh M. Patient concerns regarding chronic hepatitis B and C infection. 2008;**14**:1142–8.
28. Guirgis M, Nusair F, Bu YM, *et al.* Barriers faced by migrants in accessing healthcare for viral hepatitis infection. *Intern Med J* 2012;**42**:491–6. doi:10.1111/j.1445-5994.2011.02647.x
29. WHO. “My untold story”- a hepatitis B patient in Ghana shares his experience. 2018b. [Retrieved from: http://www.who.int/hepatitis/news-events/ghana-pr-an_untold_story/en/. Available on February 20, 2018]
30. Goffman, E. (1963). Stigma: notes on the management of social spoiled identity. Eaglewood Cliffs, NJ@ Prentice-Hall.

- 1
2
3 31. Link B, Phelan J. Stigma power. *Soc. Sci. Med.* 2014; 103: 24-
4 doi:10.1016/j.socscimed.2013.07.035
5
6
7 32. Li D, Tang T, Patterson M, *et al.* The impact of hepatitis B knowledge and stigma on
8 screening in Canadian Chinese persons. 2012;**26**:597–602.
9
10
11 33. Rafique I, Saqib MAN, Siddiqui S, *et al.* Experiences of stigma among hepatitis B and
12 C patients in Rawalpindi and Islamabad, Pakistan/Expériences de stigmatisation chez
13 des patients atteints d'hépatite B et C à Rawalpindi et Islamabad (Pakistan). *East*
14 *Mediterr Heal J* 2014;**20**:796.
15
16
17 34. Adjei CA, Naab F, Donkor ES. Beyond the diagnosis: a qualitative exploration of the
18 experiences of persons with hepatitis B in the Accra Metropolis, Ghana. *BMJ Open*
19 2017;**7**:e017665. doi:10.1136/bmjopen-2017-017665
20
21
22 35. Yoo GJ, Fang T, Zola J, *et al.* Destigmatizing hepatitis B in the Asian American
23 community: Lessons learned from the San Francisco Hep B free campaign. *J Cancer*
24 *Educ* 2012;**27**:138–44. doi:10.1007/s13187-011-0252-9
25
26
27 36. Huang J, Guan ML, Balch J, *et al.* Survey of hepatitis B knowledge and stigma
28 among chronically infected patients and uninfected persons in Beijing, China. *Liver*
29 *Int* 2016;**36**:1595–603. doi:10.1111/liv.13168
30
31
32 37. Carabez RM, Swanner JA, Yoo GJ, *et al.* Knowledge and fears among Asian
33 Americans chronically infected with hepatitis B. *J Cancer Educ* 2014;**29**:522–8.
34 doi:10.1007/s13187-013-0585-7
35
36
37 38. Wada K, Smith DR, Ishimaru T. Reluctance to care for patients with HIV or
38 hepatitis B / C in Japan. *BMC Pregnancy Childbirth* 2016;**16**:1–6.
39 doi:10.1186/s12884-016-0822-2
40
41
42 39. Dehkordi AH, Mohammadi N, NikbakhatNasrabadi A. Hepatitis-related stigma in
43 chronic patients: A qualitative study. *Appl Nurs Res* 2016;**29**:206–10.
44 doi:10.1016/j.apnr.2015.04.010
45
46
47 40. Lee H, Fawcett J, Yang JH, *et al.* Correlates of Hepatitis B Virus Health-Related
48 Behaviors of Korean Americans : A Situation-Specific Nursing Theory. 2012;:315–22.
49 doi:10.1111/j.1547-5069.2012.01468.x
50
51
52 41. Shi J, Chyun D a., Sun Z, *et al.* Assessing the stigma toward chronic carriers of
53 hepatitis B virus: development and validation of a Chinese college students' stigma
54 scale. *J Appl Soc Psychol* 2013;**43**:E46–55. doi:10.1111/jasp.12040
55
56
57 42. Mohamed R, Ng CJ, Tong WT, *et al.* Knowledge, attitudes and practices among
58 people with chronic hepatitis B attending a hepatology clinic in Malaysia: a cross
59 sectional study. *BMC Public Health* 2012;**12**:601. doi:10.1186/1471-2458-12-601
60
61 43. Wallace J, McNally S, Richmond J, *et al.* Managing chronic hepatitis B: A

- 1
2
3 qualitative study exploring the perspectives of people living with chronic hepatitis B in
4 Australia. *BMC Res Notes* 2011;**4**:45. doi:10.1186/1756-0500-4-45
5
6
7
8 44. Spearman CW, Afihene M, Ally R, *et al.* Hepatitis B in sub-Saharan Africa:
9 strategies to achieve the 2030 elimination targets. *Lancet Gastroenterol Hepatol*
10 2017;**2**:2121. doi:10.1016/S2468-1253(17)30295-9
11
12
13 45. Labaree RV. Organising your Social sciences Research Paper: Types of
14 Research designs. 2009.[Retrieved from:
15 <http://libguides.usc.edu/writingguide/researchdesigns>. Available on January 25, 2018]
16
17
18 46. Ghana Statistical Service. Ghana Health Service (GHS), and ICF Macro.
19 Ghana Demographic and Health Survey 2008, Calverton, Maryland, USA: GSS, GHS,
20 and Macro International. 2009
21
22 47. Ghana Statistical Service. 2010 population projected by sex, 2010-2016. 2016.
23 Retrieved from: http://www.statsghana.gov.gh/pop_stats.html, Accessed on May 24,
24 2018]
25
26
27 48. Ministry of Health. Category: Ministry agencies. 2018. [Retrieved from:
28 <http://www.moh.gov.gh/category/ministry-agencies/>, Accessed on January 01, 2017]
29
30
31 49. Carter N, Bryant-Lukosius D, DiCenso A, *et al.* The Use of Triangulation in
32 Qualitative Research. *Oncol Nurs Forum* 2014;**41**:545–7. doi:10.1188/14.ONF.545-
33 547
34
35
36 50. Etikan I, Musa SA, Alkassim RS. Comparison of Convenience Sampling and
37 Purposive Sampling. 2016;**5**:1–4. doi:10.11648/j.ajtas.20160501.1
38
39
40 51. Palinkas L a, Horwitz SM, Green C a, *et al.* Purposeful Sampling for Qualitative
41 Data Collection and Analysis in Mixed Method Implementation Research. *Adm Policy*
42 *Ment Heal* 2015;**42**:533–44. doi:10.1007/s10488-013-0528-y.Purposeful
43
44
45 52. Wellings K, Branigan P, Mitchell K. Discomfort, discord and discontinuity as data:
46 Using focus groups to research sensitive topics. *Cult Heal Sex* 2000;**2**:255–67.
47 doi:10.1080/136910500422241
48
49
50 53. Polit DF, Beck CT. Nursing research: Principles and methods (8TH
51 Edition). 2014. Lippincot William & Wilkins.
52
53
54 54. Valizadeh L, Zamanzadeh V, Bayani M, Zabihi A. The Social Stigma Experience in
55 Patients With Hepatitis B Infection. *Gastroenterol Nurs* [Internet]. 2017;**40**(2):143–50.
56 Available from: <http://insights.ovid.com/crossref?an=00001610-201703000-00009>
57
58
59 55. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis:
60 Implications for conducting a qualitative descriptive study. *Nurs Heal Sci*.
2013;**15**(3):398–405.

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2
3
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45
46
47
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49
50
51
52
53
54
55
56
57
58
59
60
56. Eguchi H, Wada K. Knowledge of HBV and HCV and Individuals' Attitudes Toward HBV- and HCV-Infected Colleagues: A National Cross-Sectional Study among a Working Population in Japan. *PLoS One* 2013;**8**:1–7. doi:10.1371/journal.pone.0076921
 57. Dahl TFM, Cowie BC, Biggs B, *et al.* Health literacy in patients with chronic hepatitis B attending a tertiary hospital in Melbourne : a questionnaire based survey. 2014;:1–9.
 58. Dam L, Cheng A, Tran P, *et al.* Hepatitis B stigma and knowledge among Vietnamese in Ho Chi Minh City and Chicago. *Can J Gastroenterol Hepatol* 2016;**2016**. doi:10.1155/2016/1910292
 59. Kan Q, Wen J, Xue R. Discrimination against people with hepatitis B in China. *Lancet* 2015;**386**:245–6. doi:10.1016/S0140-6736(15)61276-4
 60. Ochu CL, Beynon CM. Hepatitis B vaccination coverage, knowledge and sociodemographic determinants of uptake in high risk public safety workers in Kaduna State, Nigeria: A cross sectional survey. *BMJ Open* 2017;**7**:1–10. doi:10.1136/bmjopen-2017-015845
 61. Schillie S, Vellozzi C, Reingold A, Harris A, Haber P, Ward JW, Nelson NP. Prevention of hepatitis B virus infection in the United States: Recommendations of the Advisory Committee on Immunisation Practices. MMWR Report. 2018. [Retrieved from <https://www.cdc.gov/mmwr/volumes/67/rr/rr6701a1.htm>. Available on February 20, 2018]
 62. Hajarizadeh B, Wallace J, Richmond J, *et al.* Hepatitis B knowledge and associated factors among people with chronic hepatitis B. *Aust N Z J Public Health* 2015;**39**:563–8. doi:10.1111/1753-6405.12378
 63. Upadhyaya N, Chang R, Davis C, *et al.* Chronic hepatitis B: Perceptions in Asian American communities and diagnosis and management practices among primary care physicians. *Postgrad Med* 2010;**122**:165–75. doi:10.3810/pgm.2010.09.2213
 64. WHO. Guidelines for the prevention, care and treatment of persons with chronic hepatitis B infection. 2015;:166.
 65. Yang T, Wu MC. Discrimination against hepatitis B carriers in China. *Lancet* 2011;**378**:1059. doi:10.1016/S0140-6736(11)61460-8
 66. Yu L, Wang J, Zhu D, *et al.* Hepatitis B-related knowledge and vaccination in association with discrimination against hepatitis B in rural China. *Hum Vaccines Immunother* 2016;**12**:70–6. doi:10.1080/21645515.2015.1069932
 67. Eldredge LKB, Markham CM, Ruiters RAC, Fernández MA, Kok G,

Parcel GS. *Planning Health Promotion Programmes: An Intervention Mapping Approach (4th Edition)*. 2016. Jossey-Bass

68. Setlhare V, Wright A, Couper I. The experiences of people living with HIV/AIDS in Gaborone, Botswana: stigma, its consequences and coping mechanisms. *South African Fam Pract* [Internet]. 2014;56(6):309–13. Available from: <http://www.tandfonline.com/doi/abs/10.1080/20786190.2014.975484>

69. Ma PHX, Chan ZCY, Loke AY. Self-Stigma Reduction Interventions for People Living with HIV/AIDS and Their Families: A Systematic Review [Internet]. *AIDS and Behavior*. Springer US; 2018. Available from: <https://doi.org/10.1007/s10461-018-2304-1>

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

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For peer review only

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**

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3 4. What do people perceive individuals with hepatitis B infection as? **Probe**
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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			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

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

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.

BMJ Open

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

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Primary Subject Heading:	Gastroenterology and hepatology
Secondary Subject Heading:	Gastroenterology and hepatology, Infectious diseases, Public health
Keywords:	Hepatitis B, Ghana, Qualitative study, Belief, Stigma

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Manuscripts

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

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3 that Hepatitis B is caused by curses. Stigmatisation manifested as avoidance and social
4 isolation (discrimination). In healthcare settings, stigmatisation manifested as excessive
5 cautiousness, procedure postponement or avoidance, task-shifting, and breaches of
6 confidentiality.
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9 **Conclusions:** Given the prevalence of incorrect knowledge, as reflected in the beliefs about
10 Hepatitis B, we recommend public awareness campaigns that emphasise Hepatitis B
11 transmission routes. Also, given the manifestations of the stigma in healthcare settings, we
12 recommend the development and implementation of a continuing professional development
13 programme on Hepatitis B and adjusted policy on Hepatitis B vaccination for HCPs.
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16 **Key words:** Hepatitis B, Ghana, stigma, beliefs.
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19 **Strengths and limitations of this study**

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

40 Hepatitis B viral (HBV) infection remains a public health challenge affecting approximately
41 248 million people worldwide.¹ Globally, about 887,000 deaths attributable to complications
42 of Hepatitis B (i.e. hepatocellular carcinoma and cirrhosis) were recorded in 2015.² Sub-
43 Saharan Africa is disproportionately affected² as evidenced by the high HBV prevalence in
44 the region.³⁻⁶
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48 Within the Ghanaian context, several studies have estimated Hepatitis B prevalence above 8%.³
49 ⁷⁻¹² In fact, the most recent prevalence estimate of Hepatitis B in Ghana is 12.3%.³ HBV
50 transmission occurs through several means.^{1 13} In high endemic countries such as Ghana,
51 Hepatitis B is predominantly transmitted perinatally.¹³ Other practices, including but not
52 limited to, unsafe injections, blood transfusions, dialysis, needle stick injuries, intimate sexual
53 contact, and non-sexual contact are postulated as a vehicle for HBV transmission.¹³ Perhaps,
54 challenges such as the high cost of testing and treatment, poor referral systems, a lack of HBV
55 management guidelines, and inadequate infrastructure for screening contribute to the high
56 prevalence of Hepatitis B in developing countries, including Ghana.¹⁴⁻¹⁶
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5 Generally, conditions with some risk of transmission are associated with stigma.^{17 18} This is
6 well reported for conditions such as Tuberculosis and HIV.¹⁹⁻²² Similarly, people with chronic
7 Hepatitis B (PWHB) are likely to be stigmatised.²³⁻²⁹ Goffman,³⁰ in his seminal work, described
8 stigmatisation as a socially and culturally constituted process whereby a person is first labelled
9 as different and then devalued, leading to status loss and discrimination. Link and Phelan³¹ also
10 outlined three main motivations for stigmatisation namely exploitation and domination
11 (keeping people down), enforcement of social norms (keeping people in), and avoidance of
12 diseases (keeping people away). Exploitation and domination occur when a group dominate or
13 exploit another by virtue of their wealth, power, and high social status. Enforcement of social
14 norms centres on written and unwritten rules that people are expected to follow and those who
15 violate these norms are stigmatized.³¹ Because Hepatitis B is an infectious disease, the third
16 motivation for stigmatisation, disease avoidance, is most likely. This is supported by evidence
17 from Canada and Pakistan showing that PWHB experience stigma because of the perceived
18 infectiousness of HBV.³²⁻³³ However, research also supports the contention that stigmatisation
19 of PWHB may be motivated by a desire to enforce social norms as Hepatitis B has been
20 reported to be considered the consequence of promiscuous behaviour.^{29 34 35} Further, given that
21 HBV can be transmitted through intimate sexual contact, the enforcement of social norms as a
22 motivation for stigmatization could be particularly relevant in Ghana, where the majority of
23 the population are Christians and Muslims who disapprove of pre-marital sex.³⁴ In addition, a
24 lack of knowledge about HBV routes of transmission has been found to also contribute to
25 Hepatitis B stigma in other locales, such as China.³⁶

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

The stigmatisation of PWHB has substantial consequences. It has been found to create an environment of secrecy and denial, can lead to depression, and can be a barrier to 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 findings⁵². 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

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3 the confidential and voluntary nature of their participation. In addition, permission was sought
4 from participants to record the interview/FGD. Field notes were taken during the interviews
5 and the FGDs.
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8 Data were collected between February and November 2017. In total, 18 in-depth interviews
9 were conducted with PWHB and 15 in-depth interviews with HCPs. Additionally, 4 FGD with
10 a composition of 8 HCPs in each group were conducted. The interviews involving PWHB and
11 HCPs lasted between 45 minutes and 1 hour whereas the FGDs with HCPs lasted
12 approximately 1 hour and 15 minutes. Data saturation was reached after the interview of the
13 14th PWHB and 12th HCP.⁵²
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17 **Research Instrument**

18 The interview and FGD were guided by a semi-structured protocol with the flexibility to probe.
19 The protocol was developed based on empirical literature on Hepatitis B stigma⁵⁴ and then
20 reviewed by an expert in stigma (SS). Subsequently, the interview protocol was piloted with
21 two PWHB and two HCPs. Topics explored during the interviews with PWHB included: (1)
22 participants' experiences with being treated differently because of their HBV sero-positivity
23 and the settings in which those experiences took place; (2) perceived reasons for being treated
24 differently; and (3) the impact of those experiences. Topics explored in the interviews and
25 FGDs with HCPs were: (1) perceptions about Hepatitis B; (2) the extent to which they have
26 provided care to someone with Hepatitis B; (3) their reactions to PWHB; and (4) possible
27 reasons for possible negative reactions to PWHB. A detailed interview protocol can be found
28 in the supplementary material 1.
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34 **Data Analysis**

35 Data were processed with QSR Nvivo version 10.0 and analysed using inductive thematic
36 analysis.⁵⁵ The first author (CAA) played and listened to the audio recordings and transcribed
37 verbatim. The first transcribed data were coded by two of the authors (CAA and SS) followed
38 by discussions on the individual codes, and, later, the categories and themes generated.
39 Consensus was reached on the codes, and the main themes and sub-themes were documented.
40 Preliminary findings were checked with two representatives of the study population to ascertain
41 if the findings were in line with their views and experiences. Two main themes and eight sub-
42 themes emerged from the data. These are summarised in Table 1.
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48 **Patient/Public Involvement**

49 Patients and the public were not involved in the development of the research questions, the
50 design, recruitment, and conduct of the study. The study results will be shared with the
51 participants and other relevant stakeholders through various social media handles, and
52 conference presentations.
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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 2¹)

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

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“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.

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“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

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3 *the news spread in the yard. Nobody was coming near her veranda because they concluded*
4 *that once the guy had Hepatitis B then the lady has also gotten it. When they are sitting in the*
5 *yard and she comes to sit, they all enter their rooms. Nobody was going close to her until she*
6 *had a quarrel with one of the residents and she was insulted as having Hepatitis B. That was*
7 *when the lady got to know why everybody was avoiding her.” (HCP, North-FGD 4)*
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11 Additionally, participants indicated that family members sometimes distance themselves
12 because they see distancing themselves as a way of escaping the wrath of the gods, reflecting
13 again the belief that Hepatitis B can be the result of a curse from the gods.
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16 *“People fear to be closer to someone who has been cursed so they withdraw from the person*
17 *in order not to attract the anger of the gods.” (HCP, North-FGD 27)*
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20 21 **Social isolation**

22 Participants also reported social isolation as a manifestation of stigma. They reported that, in
23 some senior high schools where students reside in the dormitories, those with chronic Hepatitis
24 B are isolated from their peers in an effort to prevent possible transmission of the virus to other
25 students. One HCP narrated an encounter she had with a man, whose son suffered this treatment
26 in school, as follows:
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30 *“I met one man who was lamenting that his son in a senior high school was ejected from the*
31 *school dormitory because he tested Hepatitis B positive. The boy has been isolated and now*
32 *sleeps in the classroom. The school authorities feel that, if they don’t isolate those who are*
33 *positive, they will end up infecting everybody and more students. Parents are compelled to get*
34 *houses outside school campus for such students.” (HCP, North-FGD 14)*
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38 Participants also indicated that, in some parts of Northern Ghana, people who test Hepatitis B
39 positive are subsequently confined to their rooms. They are treated as outcasts and have many
40 social restrictions. Additionally, some PWHB reported having family roles taken from them
41 and being denied participation in family functions. A participant with chronic Hepatitis B
42 shared her observations as follows:
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46 *“The person is isolated when family members are made aware of his/her Hepatitis B positive*
47 *status. If they were cooking in one pot, the person ceases to cook with them. They give them*
48 *their own room and sometimes put the person very far away. They [PWHB] don’t move around*
49 *and always stay inside mourning their dead when not dead. They only come and throw their*
50 *food to them to take and eat. They won’t let you feel that you are also normal like them.”*
51 *(PWHB, North-DI 8)*
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55 Similarly, a HCP recounted her experience with a family that nearly ex-communicated their
56 daughter because of fear of possible transmission of the virus to other relations.
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3 *“I had a fourteen-year-old pregnant lady who had Hepatitis B. I counselled her and the mother.*
4 *When they returned to the house, the father denied the girl opportunity to stay with them to*
5 *prevent others getting infected. The father thought that people with Hepatitis B are not*
6 *supposed to eat with anyone and the person must use a separate bowl, cups etc. Based on this,*
7 *he could not accept the girl in the house for fear of passing on the infection to the entire family.”*
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9 (HCP, North-FGD 21)
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12 The social isolation of PWHB was additionally reported to occur in healthcare settings. In this
13 context, social isolation occurred because, according to participants, people tend to believe, as
14 reported above, that an infected person can pass the infection to others through sweat. This was
15 claimed to motivate HCPs actions to separate PWHB from other patients. *“We put them*
16 *[PWHB] at the extreme corner where no one goes there.”* (HCP, North-IDI 3)
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19 Isolation of PWHB was also reported to worsen when PWHB exhibit severe forms of
20 jaundice.
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24 *“Some people feel that when you have Hepatitis B and you look yellowish, it means that the*
25 *viruses are too many in your blood. At that point, everyone withdraws. When the person dies,*
26 *they don’t waste time to keep his/her body for proper funeral but quickly bury the person. I*
27 *have seen a number of cases like that in my village.”* (PWHB, North-IDI 3)
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30 31 **Stigmatisation in health care settings**

32 Specific manifestations of stigma in health care settings were reported as well. In healthcare
33 settings, stigma was reported to not only manifest as avoidance and social isolation as outlined
34 above, but also as excessive cautiousness, task-shifting, procedure postponement and
35 avoidance, and breaches of confidentiality.
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38 39 **Excessive cautiousness**

40 Participants reported that excessive cautiousness was taken by HCPs when providing care to
41 patients with chronic Hepatitis B. This was evidenced by the use of extreme infection
42 prevention precautions. In some instances, HCPs stated that they wore extra gloves to prevent
43 possible acquisition of the virus.
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47 *“Anytime I am managing someone with Hepatitis B, I am extra careful. I put on more than one*
48 *glove and also wash my hands regularly.”* (HCP, South-FGD 20)
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51 Another HCP explained how this is related to the belief that Hepatitis B is highly contagious.
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53 *“When you get to know that the patient has Hepatitis B infection, the mind-set changes outright.*
54 *You become very cautious because you are afraid of getting infected.”* (HCP, South-IDI 9)
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57 Notwithstanding, some HCPs indicated that their actions were dependent on the kind of
58 procedure.
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“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

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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 colleagues³³ indicated that PWHB experienced stigmatising reactions from their families who feared infection and thus refused to share eating and drinking utensils,

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3 as well as soap and towels, with relatives living with chronic Hepatitis B. That sweat was
4 considered to be an important source of HBV transmission leading to avoidance of PWHB has
5 also previously been documented by a study conducted in Nigeria.⁶⁰ However, sweat is not a
6 vehicle for HBV transmission⁶¹ and this suggests a knowledge deficit regarding Hepatitis B
7 transmission not only among the general public in Ghana but also among HCPs. This is
8 particularly disconcerting given that HCPs are considered an important source of Hepatitis B
9 information by their patients.⁶²

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13 Our study further showed that the belief that Hepatitis B is very severe is also present in Ghana
14 and that this belief contributes to stigmatisation. Generally, participants perceived Hepatitis B
15 as deadly and reported that others think PWHB will inevitably die. The belief that Hepatitis B
16 is very severe is consistent with a study conducted by Upadhyaya et al.⁶³ in the United States,
17 where the role and attitudes of primary care physicians in Hepatitis B diagnosis and treatment
18 were assessed. The results showed that physicians perceived Hepatitis B as very serious.⁶³
19 Interestingly, in our study, and in previous studies conducted in Ghana³⁴ and in the
20 Netherlands,⁶⁴ Hepatitis B was associated with, and perceived to be even more severe, than
21 HIV. It is possible that in the Ghanaian context, this is attributable to the fact that Hepatitis B
22 is not optimally managed. Unlike HIV, antiretroviral treatment for Hepatitis B is not readily
23 available and affordable.^{16 44} Additionally, the number of specialised clinics that can monitor
24 and support PWHB is inadequate³⁴ and the WHO policy on treatment, management, and
25 support of PWHB in Ghana has not yet been implemented.^{65 34} Further, with the exception of
26 Hepatitis B testing, which is covered by the national health insurance scheme when requested
27 by physicians, Hepatitis B vaccination is offered at a fee in Ghana. The only national policy on
28 Hepatitis B prevention in Ghana is the administration of Hepatitis B pentavalent vaccine to
29 newborn babies at 6, 10, and 14 weeks after birth.³⁴

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

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48 In addition to documenting beliefs about Hepatitis B that contribute to stigmatisation, we also
49 explored the manifestations of Hepatitis B stigma in Ghana. One manifestation was avoidance.
50 This is consistent with other studies.^{55 57} For example, in a study conducted in Japan with a
51 sample of the working population, Eguchi and Wada⁵⁵ found that 32.1% of their study
52 participants avoided physical contact with colleagues after learning their HBV positive status.
53 Similarly, in an Iranian study, patients with Hepatitis B reported believing that saliva is a source
54 of Hepatitis B infection and therefore avoiding bodily contact with close relations including
55 kissing.⁵⁹

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3 In our study, we also found that stigma manifests as social isolation. Our finding that students
4 were isolated from other students in school dormitories because of their Hepatitis B status is
5 similar to a finding from a study in China where a university student with Hepatitis B was put
6 in a single room instead of a shared dormitory.⁵⁸ In an study by Yang and Wu⁶⁷ the findings
7 showed that some universities and kindergartens in China refused to admit prospective students
8 who were Hepatitis B positive.
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12 Our study also looked specifically at Hepatitis B stigma in healthcare settings. We ascertained
13 that stigmatisation took form as excessive cautiousness, procedure postponement or avoidance,
14 task-shifting, and breaches of confidentiality. Perhaps inadequate knowledge and fear of
15 acquisition of HBV among the HCPs led to the excessive cautiousness and fear. Currently,
16 there is no Hepatitis B vaccination policy in place for HCPs in Ghana. HCPs therefore freely
17 choose to vaccinate against the HBV based on their willingness and financial means to do so
18 because the vaccination is not free. Our finding that HCP use excessive precautions due to fear
19 of acquisition of HBV by the HCPs found in this study has been previously documented by Yu
20 and colleagues⁶⁸ in China. Similarly, Wada et al.³⁸, in their study conducted in Japan, reported
21 that some nurses were also reluctant to care for PWHB due to a perceived risk of infection. In
22 another study conducted in Iran with chronic Hepatitis B patients by Dehkordi and others³⁹,
23 nurses and doctors were reported to be hesitant caring for PWHB after realising they have
24 Hepatitis B.
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30 Our findings have important practical implications. First, the findings provide important insight
31 on how to go about reducing Hepatitis B stigma. Given the prevalence of incorrect knowledge,
32 as reflected in the beliefs about Hepatitis B, we recommend public awareness campaigns that
33 emphasize Hepatitis B transmission routes. Also, given the manifestations of the stigma in the
34 healthcare settings, we feel that a continuing professional development programme for HCP
35 on Hepatitis B is called for as this can enhance HCPs knowledge in parallel to public awareness
36 campaigns. Additionally, we recommend the development and implementation of policy on
37 HBV vaccination for HCPs that makes this free to HCP, as this may increase HCPs confidence
38 when caring for PWHB. In developing public awareness campaigns and professional
39 development program, we consider it important to do this based on both theory and evidence
40 and in collaboration with target populations, as this improves the likelihood that these
41 interventions will effectively reduce Hepatitis B stigma in Ghana.⁶⁹ In addition, we recommend
42 providing PWHB with counselling where they can learn to use effective coping strategies when
43 confronted with stigma. Such coping strategies include seeking social support, affiliating with
44 others with Hepatitis B, religious coping, and positive reappraisal. These coping strategies have
45 been shown to build resilience against the negative effects of stigmatization.^{19 70} Additionally,
46 it may be beneficial to explore the possible use or adaptation of existing effective stigma
47 reduction interventions for PWHB such as psycho-educational interventions that focus on
48 education, skill building, empowerment, and social support.⁷¹
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56 The findings of this study should be viewed in light of a few limitations. Although this study
57 provided insights into the beliefs contributing to Hepatitis B stigma and the manifestations of
58 stigma in Ghana, it did not establish the extent to which these beliefs are endorsed or how often
59 manifestations of stigma occur. We therefore recommend investigating belief endorsement
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3 and the prevalence of stigma manifestations quantitatively in a large representative sample of
4 the Ghanaian population. Second, given that PWHB participants had lived with the infection
5 for a period between one and seven years, and were asked to recall their experiences
6 retrospectively, there was potential for recall bias. We, however, sought to reduce this by
7 asking follow-up questions to confirm or verify participants' experiences. The third possible
8 limitation of this study was the exclusion of PWHB who were in the terminal stage of the
9 disease. We recognise that their experiences with stigma might differ from our study
10 participants.
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14 **Conclusion**

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

36 HBV- Hepatitis B Virus; PWHB- People with Hepatitis B; HCPs – Healthcare Providers; IDI
37 – In-depth Interviews; FGD – Focus Group Discussions
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41 No funding
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44 **Availability of data and materials:** Participants have consented for anonymised transcripts to
45 be shared upon request.
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48 **Authors Contribution:** CAA conceptualised the study. CAA, SES, RACR, FN designed the
49 study. Interview guide was designed by CAA and SES. Data analysis was done by CAA and
50 SES. Manuscript was critically reviewed by SES, FN, RACR. All authors read and approved
51 the manuscript.
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54 **Competing interests:** The authors declare no conflict of interest in this study.

55 **Consent for publication:** Not applicable
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58 **Ethical Approval**

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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.

References

1. Schweitzer A, Horn J, Mikolajczyk RT, *et al.* Estimations of worldwide prevalence of chronic hepatitis B virus infection: A systematic review of data published between 1965 and 2013. *Lancet* 2015;386:1546–55. doi:10.1016/S0140-6736(15)61412-X
2. WHO. Hepatitis B Fact Sheet. 2018a. [Retrieved from: <http://www.who.int/mediacentre/factsheets/fs204/en/>. Available on February 06, 2018]
3. Ofori-Asenso R, Agyeman AA. Hepatitis B in Ghana: a systematic review & meta-analysis of prevalence studies (1995-2015). *BMC Infect Dis* 2016;16:130. doi:10.1186/s12879-016-1467-5
4. Musa BM, Bussell S, Borodo MM, *et al.* Prevalence of hepatitis B virus infection in Nigeria, 2000-2013: a systematic review and meta-analysis. *Niger J clin Pr* 2015;18:163–72. doi:10.4103/1119-3077.151035
5. Kolou M, Katawa G, Salou M, *et al.* High Prevalence of Hepatitis B Virus Infection in the Age Range of 20-39 Years Old Individuals in Lome. 2015;:1–7. doi:10.2174/1874357901710011001
6. Bigna JJ, Amougou MA, Asangbeh SL, *et al.* Seroprevalence of hepatitis B virus infection in Cameroon : a systematic review and meta-analysis. 2017;:1–12. doi:10.1136/bmjopen-2016-015298
7. Rufai T, Mutocheluh M, Kwarteng K, *et al.* The prevalence of hepatitis B virus E antigen among Ghanaian blood donors. *Pan Afr Med J* 2014;17:53. doi:10.11604/pamj.2014.17.53.3390
8. Mutocheluh M, Owusu M, Kwofie TB, *et al.* Risk factors associated with hepatitis B exposure and the reliability of five rapid kits commonly used for screening blood donors in Ghana. *BMC Res Notes* 2014;7:1–8. doi:10.1186/1756-0500-7-8739.
9. Sagoe KWC, Agyei AA, Ziga F, Lartey M, Adiku TK, Seshi M, Arens MQ, Mingle J A A. Prevalence and Impact of Hepatitis B and C Virus Co-Infections in Antiretroviral Treatment Naive Patients with HIV Infection at a Major Treatment Center in Ghana. *Journal of Medical Virology* 2012; 84: 6-10

10. Adjei AA, Armah HB, Gbagbo F, *et al.* Correlates of HIV, HBV, HCV and syphilis infections among prison inmates and officers in Ghana: A national multicenter study. *BMC Infect Dis* 2008;**8**:1–12. doi:10.1186/1471-2334-8-33
11. Candotti D, Danso K, Allain J-P. Maternofetal transmission of hepatitis B virus genotype E in Ghana, west Africa. *J Gen Virol* 2007;**88**:2686–95. doi:10.1099/vir.0.83102-0
12. Cho Y, Bonsu G, Akoto-Ampaw A, *et al.* The prevalence and risk factors for hepatitis B surface Ag positivity in pregnant women in eastern region of Ghana. *Gut Liver* 2012;**6**:235–40. doi:10.5009/gnl.2012.6.2.235
13. Trépo C, Chan HLY, Lok A. Hepatitis B virus infection. *Lancet* 2014;**6736**:1–11. doi:10.1016/S0140-6736(14)60220-8
14. Giles-Vernick T, Hejoaka F, Sanou A, Shimakawa Y, Bamba I, Traoré A. Barriers to Linkage to Care for Hepatitis B Virus Infection: A Qualitative Analysis in Burkina Faso, West Africa. *Am J Trop Med Hyg* 2016;**95**:1368–75. doi:10.4269/ajtmh.16-0398
15. Lemoine M, Eholié S, Lacombe K. Reducing the neglected burden of viral hepatitis in Africa: Strategies for a global approach. *J Hepatol* 2015;**62**:469–76. doi:10.1016/j.jhep.2014.10.008
16. Nwokediuko SC. Chronic Hepatitis B : Management Challenges in Resource-Poor Coun- tries. 2011;**11**:786–93. doi:10.5812/kowsar.1735143X.757
17. Butt G, Paterson BL, McGuinness LK. Living with the stigma of hepatitis C. *West J Nurs Res* 2008;**30**:204–21. doi:10.1177/0193945907302771
18. Sandelowski, M., Lambe, C., & Barroso, J. (2004). Stigma in HIV-Positive Women. *J Nurs Scholarsh.*, 2004;36 (2):122-8
19. Stutterheim SE, Bos AER, Shiripinda I, *et al.* HIV-related stigma in African and Afro-Caribbean communities in the Netherlands : Manifestations , consequences , and coping. *Psychol Health* 2012;**27**:1–32. doi:10.1080/08870446.2011.585426
20. Colombini M, Mutemwa R, Kivunaga J, *et al.* Experiences of stigma among women living with HIV attending sexual and reproductive health services in Kenya : a qualitative study. 2014:1–9.
21. Courtwright A, Turner NA. Tuberculosis and Stigmatization :Pathways and Interventions. *Public Health Reports* 2010;**125**:34–42.

- 1
2
3 22. Miller C, Huston J, Samu L, *et al.* ‘ It makes the patient’s spirit weaker’: tuberculosis
4 stigma and gender interaction in Dar es Salaam , Tanzania. *Int. J Tuberc Lung Dis*
5 2017;**21**:42–9.
6
7
8 23. Cotler SJ, Cotler S, Xie H, *et al.* Characterizing hepatitis B stigma in Chinese
9 immigrants. *J Viral Hepat* 2012;**19**:147–52. doi:10.1111/j.1365-2893.2011.01462.x
10
11
12 24. Ellard, J. & Wallace J. (2013). Stigma and discrimination and hepatitis B: A review
13 of current research. *ARCSHS Monographs Series*, 93
14
15
16 25. Ng CJ, Low WY, Wong LP, *et al.* Uncovering the experiences and needs of patients
17 with chronic hepatitis B infection at diagnosis: a qualitative study. *Asia Pac J Public*
18 *Health* 2013;**25**:32–40. doi:10.1177/1010539511413258
19
20
21 26. Wu H, Yim C, Chan A, *et al.* Sociocultural factors that potentially affect the
22 institution of prevention and treatment strategies for hepatitis B in Chinese Canadians.
23 *Can J Gastroenterol* 2009;**23**:31–6.
24
25
26 27. Alizadeh a HM, Ranjbar M, Yadollahzadeh M. Patient concerns regarding chronic
27 hepatitis B and C infection. 2008;**14**:1142–8.
28
29
30 28. Guirgis M, Nusair F, Bu YM, *et al.* Barriers faced by migrants in accessing healthcare
31 for viral hepatitis infection. *Intern Med J* 2012;**42**:491–6. doi:10.1111/j.1445-
32 5994.2011.02647.x
33
34
35 29. WHO. “My untold story”- a hepatitis B patient in Ghana shares his
36 experience. 2018b. [Retrieved from: [http://www.who.int/hepatitis/news-](http://www.who.int/hepatitis/news-events/ghana-pr-an_untold_story/en/)
37 [events/ghana-pr-an_untold_story/en/](http://www.who.int/hepatitis/news-events/ghana-pr-an_untold_story/en/). Available on February 20, 2018]
38
39
40 30. Goffman, E. (1963). Stigma: notes on the management of social spoiled identity.
41 *Eaglewood Cliffs, NJ@ Prentice-Hall.*
42
43
44 31. Link B, Phelan J. Stigma power. *Soc. Sci. Med.* 2014; 103: 24-
45 doi:10.1016/j.socscimed.2013.07.035
46
47
48 32. Li D, Tang T, Patterson M, *et al.* The impact of hepatitis B knowledge and stigma on
49 screening in Canadian Chinese persons. 2012;**26**:597–602.
50
51
52 33. Rafique I, Saqib MAN, Siddiqui S, *et al.* Experiences of stigma among hepatitis B and
53 C patients in Rawalpindi and Islamabad, Pakistan/Expériences de stigmatisation chez
54 des patients atteints d’hépatite B et C à Rawalpindi et Islamabad (Pakistan). *East*
55 *Mediterr Heal J* 2014;**20**:796.
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55
56
57
58
59
60
34. Adjei CA, Naab F, Donkor ES. Beyond the diagnosis: a qualitative exploration of the experiences of persons with hepatitis B in the Accra Metropolis, Ghana. *BMJ Open* 2017;**7**:e017665. doi:10.1136/bmjopen-2017-017665
 35. Yoo GJ, Fang T, Zola J, *et al.* Destigmatizing hepatitis B in the Asian American community: Lessons learned from the San Francisco Hep B free campaign. *J Cancer Educ* 2012;**27**:138–44. doi:10.1007/s13187-011-0252-9
 36. Huang J, Guan ML, Balch J, *et al.* Survey of hepatitis B knowledge and stigma among chronically infected patients and uninfected persons in Beijing, China. *Liver Int* 2016;**36**:1595–603. doi:10.1111/liv.13168
 37. Carabez RM, Swanner JA, Yoo GJ, *et al.* Knowledge and fears among Asian Americans chronically infected with hepatitis B. *J Cancer Educ* 2014;**29**:522–8. doi:10.1007/s13187-013-0585-7
 38. Wada K, Smith DR, Ishimaru T. Reluctance to care for patients with HIV or hepatitis B / C in Japan. *BMC Pregnancy Childbirth* 2016;**16**:1–6. doi:10.1186/s12884-016-0822-2
 39. Dehkordi AH, Mohammadi N, NikbakhatNasrabadi A. Hepatitis-related stigma in chronic patients: A qualitative study. *Appl Nurs Res* 2016;**29**:206–10. doi:10.1016/j.apnr.2015.04.010
 40. Lee H, Fawcett J, Yang JH, *et al.* Correlates of Hepatitis B Virus Health-Related Behaviors of Korean Americans : A Situation-Specific Nursing Theory. 2012;**31**:5–22. doi:10.1111/j.1547-5069.2012.01468.x
 41. Shi J, Chyun D a., Sun Z, *et al.* Assessing the stigma toward chronic carriers of hepatitis B virus: development and validation of a Chinese college students' stigma scale. *J Appl Soc Psychol* 2013;**43**:E46–55. doi:10.1111/jasp.12040
 42. Mohamed R, Ng CJ, Tong WT, *et al.* Knowledge, attitudes and practices among people with chronic hepatitis B attending a hepatology clinic in Malaysia: a cross sectional study. *BMC Public Health* 2012;**12**:601. doi:10.1186/1471-2458-12-601
 43. Wallace J, McNally S, Richmond J, *et al.* Managing chronic hepatitis B: A qualitative study exploring the perspectives of people living with chronic hepatitis B in Australia. *BMC Res Notes* 2011;**4**:45. doi:10.1186/1756-0500-4-45
 44. Spearman CW, Afihene M, Ally R, *et al.* Hepatitis B in sub-Saharan Africa: strategies to achieve the 2030 elimination targets. *Lancet Gastroenterol Hepatol* 2017;**2**:2121. doi:10.1016/S2468-1253(17)30295-9
 45. Labaree RV. Organising your Social sciences Research Paper: Types of Research designs. 2009.[Retrieved from: <http://libguides.usc.edu/writingguide/researchdesigns>. Availabe on January 25, 2018]
 46. Ghana Statistical Service. Ghana Health Service (GHS), and ICF Macro.

- 1
2
3 Ghana Demographic and Health Survey 2008, Calverton, Maryland, USA: GSS, GHS,
4 and Macro International. 2009
5
6
7 47. Ghana Statistical Service. 2010 population projected by sex, 2010-2016. 2016.
8 Retrieved from: http://www.statsghana.gov.gh/pop_stats.html, Accessed on May 24,
9 2018]
- 10
11 48. Ministry of Health. Category: Ministry agencies. 2018. [Retrieved from:
12 <http://www.moh.gov.gh/category/ministry-agencies/>, Accessed on January 01, 2017]
- 13
14 49. Carter N, Bryant-Lukosius D, DiCenso A, *et al.* The Use of Triangulation in
15 Qualitative Research. *Oncol Nurs Forum* 2014;**41**:545–7. doi:10.1188/14.ONF.545-
16 547
17
18
19
- 20 50. Etikan I, Musa SA, Alkassim RS. Comparison of Convenience Sampling and
21 Purposive Sampling. 2016;**5**:1–4. doi:10.11648/j.ajtas.20160501.1
22
- 23 51. Palinkas L a, Horwitz SM, Green C a, *et al.* Purposeful Sampling for Qualitative
24 Data Collection and Analysis in Mixed Method Implementation Research. *Adm Policy*
25 *Ment Heal* 2015;**42**:533–44. doi:10.1007/s10488-013-0528-y.Purposeful
26
27
28
- 29 52. Polit DF, Beck CT. Nursing research: Principles and methods (8TH
30 Edition). 2014. Lippincot William & Wilkins.
31
- 32 53. Wellings K, Branigan P, Mitchell K. Discomfort, discord and discontinuity as data:
33 Using focus groups to research sensitive topics. *Cult Heal Sex* 2000;**2**:255–67.
34 doi:10.1080/136910500422241
35
- 36 54. Valizadeh L, Zamanzadeh V, Bayani M, Zabihi A. The Social Stigma Experience in
37 Patients With Hepatitis B Infection. *Gastroenterol Nurs* [Internet]. 2017;**40**(2):143–
38 50. Available from: [http://insights.ovid.com/crossref?an=00001610-201703000-](http://insights.ovid.com/crossref?an=00001610-201703000-00009)
39 00009
40
41
- 42 55. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis:
43 Implications for conducting a qualitative descriptive study. *Nurs Heal Sci*.
44 2013;**15**(3):398–405.
45
46
47
- 48 56. Eguchi H, Wada K. Knowledge of HBV and HCV and Individuals' Attitudes
49 Toward HBV- and HCV-Infected Colleagues: A National Cross-Sectional Study
50 among a Working Population in Japan. *PLoS One* 2013;**8**:1–7.
51 doi:10.1371/journal.pone.0076921
52
- 53 57. Dahl TFM, Cowie BC, Biggs B, *et al.* Health literacy in patients with chronic hepatitis
54 B attending a tertiary hospital in Melbourne : a questionnaire based survey. 2014;:1–9.
55
- 56 58. Dam L, Cheng A, Tran P, *et al.* Hepatitis B stigma and knowledge among
57 Vietnamese in Ho Chi Minh City and Chicago. *Can J Gastroenterol Hepatol*
58 2016;**2016**. doi:10.1155/2016/1910292
59
60

- 1
2
3 59. Kan Q, Wen J, Xue R. Discrimination against people with hepatitis B in China. *Lancet* 2015;**386**:245–6. doi:10.1016/S0140-6736(15)61276-4
4
5
6
7
8 60. Ochu CL, Beynon CM. Hepatitis B vaccination coverage, knowledge and
9 sociodemographic determinants of uptake in high risk public safety workers in
10 Kaduna State, Nigeria: A cross sectional survey. *BMJ Open* 2017;**7**:1–10.
11 doi:10.1136/bmjopen-2017-015845
12
13 61. Schillie S, Vellozzi C, Reingold A, Harris A, Haber P, Ward JW,
14 Nelson NP. Prevention of hepatitis B virus infection in the United States:
15 Recommendations of the Advisory Committee on Immunisation Practices. MMWR
16 Report. 2018. [Retrieved from
17 <https://www.cdc.gov/mmwr/volumes/67/rr/rr6701a1.htm>. Available on February 20,
18 2018]
19
20
21 62. Hajarizadeh B, Wallace J, Richmond J, *et al.* Hepatitis B knowledge and
22 associated
23 factors among people with chronic hepatitis B. *Aust N Z J Public Health*
24 2015;**39**:563–8. doi:10.1111/1753-6405.12378
25
26
27 63. Upadhyaya N, Chang R, Davis C, *et al.* Chronic hepatitis B: Perceptions in Asian
28 American communities and diagnosis and management practices among primary care
29 physicians. *Postgrad Med* 2010;**122**:165–75. doi:10.3810/pgm.2010.09.2213
30
31
32 64. Hamdiui N, Stein ML, Timen A, Timmermans D, Wong A, van den Muijsenbergh
33 METC, *et al.* Hepatitis B in Moroccan-Dutch: A quantitative study into determinants
34 of screening participation. *BMC Med*. 2018;**16**(1):1–6.
35
36
37 65. WHO. Guidelines for the prevention, care and treatment of persons with chronic
38 hepatitis B infection. 2015;:166.
39
40 66. Adjei CA, Atibila F, Apiribu F, Ahordzor F, Attafuah PA, Ansah-Nyarko M,
41 Asamoah R, and Menkah W. Hepatitis B infection among parturient women in Peri-
42 Urban Ghana. *American Journal of Tropical Medicine and Hygiene*. 2018;
43 Doi:10.4269/ajtmh.17-0752.
44
45
46 67. Yang T, Wu MC. Discrimination against hepatitis B carriers in China. *Lancet*
47 2011;**378**:1059. doi:10.1016/S0140-6736(11)61460-8
48
49
50 68. Yu L, Wang J, Zhu D, *et al.* Hepatitis B-related knowledge and vaccination in
51 association with discrimination against hepatitis B in rural China. *Hum Vaccines*
52 *Immunother* 2016;**12**:70–6. doi:10.1080/21645515.2015.1069932
53
54
55 69. Eldredge LKB, Markham CM, Ruiters RAC, Fernández MA, Kok G,
56 Parcel GS. *Planning Health Promotion Programmes: An Intervention Mapping*
57 *Approach (4th Edition)*. 2016. Jossey-Bass
58
59
60

70. Setlhare V, Wright A, Couper I. The experiences of people living with HIV/AIDS in Gaborone, Botswana: stigma, its consequences and coping mechanisms. *South African Fam Pract* [Internet]. 2014;56(6):309–13. Available from: <http://www.tandfonline.com/doi/abs/10.1080/20786190.2014.975484>

71. Ma PHX, Chan ZCY, Loke AY. Self-Stigma Reduction Interventions for People Living with HIV/AIDS and Their Families: A Systematic Review [Internet]. *AIDS and Behavior*. Springer US; 2018. Available from: <https://doi.org/10.1007/s10461-018-2304-1>

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

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For peer review only

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**

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3 4. What do people perceive individuals with hepatitis B infection as? **Probe**
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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			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

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

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.

BMJ Open

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

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Keywords:	Hepatitis B, Ghana, Qualitative study, Belief, Stigma

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Manuscripts

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 affected² as evidenced by the high HBV prevalence in the region.³⁻⁶

Within the Ghanaian context, several studies have estimated Hepatitis B prevalence above 8%.³⁷⁻¹² In fact, the most recent prevalence estimate of Hepatitis B in Ghana is 12.3%.³ HBV transmission occurs through several means.¹¹³ 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

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3 Generally, conditions with some risk of transmission are associated with stigma.^{17 18} This is
4 well reported for conditions such as Tuberculosis and HIV.¹⁹⁻²² Similarly, people with chronic
5 Hepatitis B (PWHB) are likely to be stigmatised.²³⁻²⁹ Goffman,³⁰ in his seminal work, described
6 stigmatisation as a socially and culturally constituted process whereby a person is first labelled
7 as different and then devalued, leading to status loss and discrimination. Link and Phelan³¹ also
8 outlined three main motivations for stigmatisation namely exploitation and domination
9 (keeping people down), enforcement of social norms (keeping people in), and avoidance of
10 diseases (keeping people away). Exploitation and domination occur when a group of people
11 dominate or exploit another by virtue of their wealth, power, and high social status.
12 Enforcement of social norms centres on written and unwritten rules that people are expected to
13 follow and those who violate these norms are stigmatized.³¹ Because Hepatitis B is an
14 infectious disease, the third motivation for stigmatisation, disease avoidance, is most likely.
15 This is supported by evidence from Canada and Pakistan showing that PWHB experience
16 stigma because of the perceived infectiousness of HBV.³²⁻³³ However, research also supports
17 the contention that stigmatisation of PWHB may be motivated by a desire to enforce social
18 norms as Hepatitis B has been reported to be considered the consequence of promiscuous
19 behaviour.^{29 34 35} Further, given that HBV can be transmitted through intimate sexual contact,
20 the enforcement of social norms as a motivation for stigmatization could be particularly
21 relevant in Ghana, where the majority of the population are Christians and Muslims who
22 disapprove of pre-marital sex.³⁴ In addition, a lack of knowledge about HBV routes of
23 transmission has been found to also contribute to Hepatitis B stigma in other locales, such as
24 China.³⁶

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

The stigmatisation of PWHB has substantial consequences. It has been found to create an environment of secrecy and denial, can lead to depression, and can be a barrier to 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 findings⁵². 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,

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3 permission was sought from participants to record the interviews/FGDs. Field notes were taken
4 during the interviews and the FGDs.
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7 Data were collected between February and November 2017. In total, 18 in-depth interviews
8 were conducted with PWHB and 15 in-depth interviews with HCPs. Additionally, 4 FGDs with
9 a composition of 8 HCPs in each group were conducted. The interviews involving PWHB and
10 HCPs lasted between 45 minutes and 1 hour whereas the FGDs with HCPs lasted
11 approximately 1 hour and 15 minutes. Data saturation was reached after the interviews of the
12 14th PWHB and 12th HCP.⁵²
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16 **Research Instrument**

17 The interviews and FGDs were guided by a semi-structured protocol with the flexibility to
18 probe. The protocol was developed based on empirical literature on Hepatitis B stigma⁵⁴ and
19 then reviewed by an expert in stigma (SS). Subsequently, the interview protocol was piloted
20 with two PWHB and two HCPs. Topics explored during the interviews with PWHB included:
21 (1) participants' experiences with being treated differently because of their HBV sero-positivity
22 and the settings in which those experiences took place; (2) perceived reasons for being treated
23 differently; and (3) the impact of those experiences. Topics explored in the interviews and
24 FGDs with HCPs were: (1) perceptions about Hepatitis B; (2) the extent to which they have
25 provided care to someone with Hepatitis B; (3) their reactions to PWHB; and (4) possible
26 reasons for possible negative reactions to PWHB. A detailed interview protocol can be found
27 in the supplementary material 1.
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33 **Data Analysis**

34 Data were processed with QSR Nvivo version 10.0 and analysed using inductive thematic
35 analysis.⁵⁵ The first author (CAA) played and listened to the audio recordings and transcribed
36 verbatim. The first transcribed data was coded by two of the authors (CAA and SS) followed
37 by discussions on the individual codes, and, later, the categories and themes generated.
38 Consensus was reached on the codes, and the main themes and sub-themes were documented.
39 Preliminary findings were checked with two representatives of the study population to ascertain
40 if the findings were in line with their views and experiences. Two main themes and eight sub-
41 themes emerged from the data. These are summarised in Table 1.
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46 **Patient/Public Involvement**

47 Patients and the public were not involved in the development of the research questions, the
48 design, recruitment, and the conduct of the study. The study results will be shared with the
49 participants and other relevant stakeholders through various social media handles, and
50 conferences.
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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 2¹)

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

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“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.

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“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

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3 *the news spread in the yard. Nobody was coming near her veranda because they concluded*
4 *that once the guy had Hepatitis B then the lady has also gotten it. When they are sitting in the*
5 *yard and she comes to sit, they all enter their rooms. Nobody was going close to her until she*
6 *had a quarrel with one of the residents and she was insulted as having Hepatitis B. That was*
7 *when the lady got to know why everybody was avoiding her.” (HCP, North-FGD 4)*
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11 Additionally, participants indicated that family members sometimes distance themselves
12 because they see distancing themselves as a way of escaping the wrath of the gods, reflecting
13 again the belief that Hepatitis B can be the result of a curse from the gods.
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16 *“People fear to be closer to someone who has been cursed so they withdraw from the person*
17 *in order not to attract the anger of the gods.” (HCP, North-FGD 27)*
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20 21 **Social isolation**

22 Participants also reported social isolation as a manifestation of stigma. They reported that, in
23 some senior high schools where students reside in the dormitories, those with chronic Hepatitis
24 B are isolated from their peers in an effort to prevent possible transmission of the virus to other
25 students. One HCP narrated an encounter she had with a man, whose son suffered this treatment
26 in school, as follows:
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30 *“I met one man who was lamenting that his son in a senior high school was ejected from the*
31 *school dormitory because he tested Hepatitis B positive. The boy has been isolated and now*
32 *sleeps in the classroom. The school authorities feel that, if they don’t isolate those who are*
33 *positive, they will end up infecting everybody and more students. Parents are compelled to get*
34 *houses outside school campus for such students.” (HCP, North-FGD 14)*
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38 Participants also indicated that, in some parts of Northern Ghana, people who test Hepatitis B
39 positive are subsequently confined to their rooms. They are treated as outcasts and have many
40 social restrictions. Additionally, some PWHB reported having family roles taken from them
41 and being denied participation in family functions. A participant with chronic Hepatitis B
42 shared her observations as follows:
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46 *“The person is isolated when family members are made aware of his/her Hepatitis B positive*
47 *status. If they were cooking in one pot, the person ceases to cook with them. They give them*
48 *their own room and sometimes put the person very far away. They [PWHB] don’t move around*
49 *and always stay inside mourning their dead when not dead. They only come and throw their*
50 *food to them to take and eat. They won’t let you feel that you are also normal like them.”*
51 *(PWHB, North-DI 8)*
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55 Similarly, a HCP recounted her experience with a family that nearly ex-communicated their
56 daughter because of fear of possible transmission of the virus to other relations.
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3 *“I had a fourteen-year-old pregnant lady who had Hepatitis B. I counselled her and the mother.*
4 *When they returned to the house, the father denied the girl opportunity to stay with them to*
5 *prevent others getting infected. The father thought that people with Hepatitis B are not*
6 *supposed to eat with anyone and the person must use a separate bowl, cups etc. Based on this,*
7 *he could not accept the girl in the house for fear of passing on the infection to the entire family.”*
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9 (HCP, North-FGD 21)
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12 The social isolation of PWHB was additionally reported to occur in healthcare settings. In this
13 context, social isolation occurred because, according to participants, people tend to believe, as
14 reported above, that an infected person can pass the infection to others through sweat. This was
15 claimed to motivate HCPs actions to separate PWHB from other patients. *“We put them*
16 *[PWHB] at the extreme corner where no one goes there.”* (HCP, North-IDI 3)
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20 Isolation of PWHB was also reported to worsen when PWHB exhibit severe forms of
21 jaundice.
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24 *“Some people feel that when you have Hepatitis B and you look yellowish, it means that the*
25 *viruses are too many in your blood. At that point, everyone withdraws. When the person dies,*
26 *they don’t waste time to keep his/her body for proper funeral but quickly bury the person. I*
27 *have seen a number of cases like that in my village.”* (PWHB, North-IDI 3)
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30 31 **Stigmatisation in health care settings**

32 Specific manifestations of stigma in health care settings were reported as well. In healthcare
33 settings, stigma was reported to not only manifest as avoidance and social isolation as outlined
34 above, but also as excessive cautiousness, task-shifting, procedure postponement and
35 avoidance, and breaches of confidentiality.
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38 39 **Excessive cautiousness**

40 Participants reported that excessive cautiousness was taken by HCPs when providing care to
41 patients with chronic Hepatitis B. This was evidenced by the use of extreme infection
42 prevention precautions. In some instances, HCPs stated that they wore extra gloves to prevent
43 possible acquisition of the virus.
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47 *“Anytime I am managing someone with Hepatitis B, I am extra careful. I put on more than one*
48 *glove and also wash my hands regularly.”* (HCP, South-FGD 20)
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50 Another HCP explained how this is related to the belief that Hepatitis B is highly contagious.
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53 *“When you get to know that the patient has Hepatitis B infection, the mind-set changes outright.*
54 *You become very cautious because you are afraid of getting infected.”* (HCP, South-IDI 9)
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57 Notwithstanding, some HCPs indicated that their actions were dependent on the kind of
58 procedure.
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“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

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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 colleagues³³ indicated that PWHB experienced stigmatising reactions from their families who feared infection and thus refused to share eating and drinking utensils,

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3 as well as soap and towels, with relatives living with chronic Hepatitis B. That sweat was
4 considered to be an important source of HBV transmission leading to avoidance of PWHB has
5 also previously been documented by a study conducted in Nigeria.⁶⁰ However, sweat is not a
6 vehicle for HBV transmission⁶¹ and this suggests a knowledge deficit regarding Hepatitis B
7 transmission not only among the general public in Ghana but also among HCPs. This is
8 particularly disconcerting given that HCPs are considered an important source of Hepatitis B
9 information by their patients.⁶²
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13 Our study further showed that the belief that Hepatitis B is very severe is also present in Ghana
14 and that this belief contributes to stigmatisation. Generally, participants perceived Hepatitis B
15 as deadly and reported that others think PWHB will inevitably die. The belief that Hepatitis B
16 is very severe is consistent with a study conducted by Upadhyaya et al.⁶³ in the United States,
17 where the role and attitudes of primary care physicians in Hepatitis B diagnosis and treatment
18 were assessed. The results showed that physicians perceived Hepatitis B as very serious.⁶³
19 Interestingly, in our study, and in previous studies conducted in Ghana³⁴ and in the
20 Netherlands,⁶⁴ Hepatitis B was associated with, and perceived to be even more severe, than
21 HIV. It is possible that in the Ghanaian context, this is attributable to the fact that Hepatitis B
22 is not optimally managed. Unlike HIV, antiretroviral treatment for Hepatitis B is not readily
23 available and affordable.^{16 44} Additionally, the number of specialised clinics that can monitor
24 and support PWHB is inadequate³⁴ and the WHO policy on treatment, management, and
25 support of PWHB in Ghana has not yet been implemented.^{65 34} Further, with the exception of
26 Hepatitis B testing, which is covered by the national health insurance scheme when requested
27 by physicians, Hepatitis B vaccination is offered at a fee in Ghana. The only national policy on
28 Hepatitis B prevention in Ghana is the administration of Hepatitis B pentavalent vaccine to
29 newborn babies at 6, 10, and 14 weeks after birth.³⁴
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37 Another finding of this study was that, in Ghana, there is a belief that Hepatitis B is caused by
38 curses. An earlier study showed that people do attach superstitious beliefs to Hepatitis B in
39 Ghana.³⁴ Also, a study conducted by Adjei et al.⁶⁶ found that 86% ($n=168$) of participants
40 linked the cause of Hepatitis B to curses. This association is unsurprising given that some
41 clinical manifestations of Hepatitis B, including swollen abdomen and feet, are analogous to
42 the perceived outcomes of a curse in Ghanaian culture. In Ghana, people are particularly
43 cautious about handling items perceived to be cursed as not handling them can help to avoid
44 possible transfer of the consequences of that curse.
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48 In addition to documenting beliefs about Hepatitis B that contribute to stigmatisation, we also
49 explored the manifestations of Hepatitis B stigma in Ghana. One manifestation was avoidance.
50 This is consistent with other studies.^{55 57} For example, in a study conducted in Japan with a
51 sample of the working population, Eguchi and Wada⁵⁵ found that 32.1% of their study
52 participants avoided physical contact with colleagues after learning their HBV positive status.
53 Similarly, in an Iranian study, patients with Hepatitis B reported believing that saliva is a source
54 of Hepatitis B infection and therefore avoiding bodily contact with close relations including
55 kissing.⁵⁹
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3 In our study, we also found that stigma manifests as social isolation. Our finding that students
4 were isolated from other students in school dormitories because of their Hepatitis B status is
5 similar to a finding from a study in China where a university student with Hepatitis B was put
6 in a single room instead of a shared dormitory.⁵⁸ In an study by Yang and Wu⁶⁷ the findings
7 showed that some universities and kindergartens in China refused to admit prospective students
8 who were Hepatitis B positive.
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12 Our study also looked specifically at Hepatitis B stigma in healthcare settings. We ascertained
13 that stigmatisation took form as excessive cautiousness, procedure postponement or avoidance,
14 task-shifting, and breaches of confidentiality. Perhaps inadequate knowledge and fear of
15 acquisition of HBV among the HCPs led to the excessive cautiousness and fear. Currently,
16 there is no Hepatitis B vaccination policy in place for HCPs in Ghana. HCPs therefore freely
17 choose to vaccinate against the HBV based on their willingness and financial means to do so
18 because the vaccination is not free. Our finding that HCP use excessive precautions due to fear
19 of acquisition of HBV by the HCPs found in this study has been previously documented by Yu
20 and colleagues⁶⁸ in China. Similarly, Wada et al.³⁸, in their study conducted in Japan, reported
21 that some nurses were also reluctant to care for PWHB due to a perceived risk of infection. In
22 another study conducted in Iran with chronic Hepatitis B patients by Dehkordi and others³⁹,
23 nurses and doctors were reported to be hesitant caring for PWHB after realising they have
24 Hepatitis B.
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30 Our findings have important practical implications. First, the findings provide important insight
31 on how to go about reducing Hepatitis B stigma. Given the prevalence of incorrect knowledge,
32 as reflected in the beliefs about Hepatitis B, we recommend public awareness campaigns that
33 emphasize Hepatitis B transmission routes. Also, given the manifestations of the stigma in the
34 healthcare settings, we feel that a continuing professional development programme for HCP
35 on Hepatitis B is called for as this can enhance HCPs knowledge in parallel to public awareness
36 campaigns. Additionally, we recommend the development and implementation of policy on
37 HBV vaccination for HCPs that makes this free to HCP, as this may increase HCPs confidence
38 when caring for PWHB. In developing public awareness campaigns and professional
39 development program, we consider it important to do this based on both theory and evidence
40 and in collaboration with target populations, as this improves the likelihood that these
41 interventions will effectively reduce Hepatitis B stigma in Ghana.⁶⁹ In addition, we recommend
42 providing PWHB with counselling where they can learn to use effective coping strategies when
43 confronted with stigma. Such coping strategies include seeking social support, affiliating with
44 others with Hepatitis B, religious coping, and positive reappraisal. These coping strategies have
45 been shown to build resilience against the negative effects of stigmatization.^{19 70} Additionally,
46 it may be beneficial to explore the possible use or adaptation of existing effective stigma
47 reduction interventions for PWHB such as psycho-educational interventions that focus on
48 education, skill building, empowerment, and social support.⁷¹
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56 The findings of this study should be viewed in light of a few limitations. Although this study
57 provided insights into the beliefs contributing to Hepatitis B stigma and the manifestations of
58 stigma in Ghana, it did not establish the extent to which these beliefs are endorsed or how often
59 manifestations of stigma occur. We therefore recommend investigating belief endorsement and
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3 the prevalence of stigma manifestations quantitatively in a large representative sample of the
4 Ghanaian population. Second, given that PWHB participants had lived with the infection for a
5 period between one and seven years, and were asked to recall their experiences retrospectively,
6 there was potential for recall bias. We, however, sought to reduce this by asking follow-up
7 questions to confirm or verify participants' experiences. The third possible limitation of this
8 study was the exclusion of PWHB who were in the terminal stage of the disease. We recognise
9 that their experiences with stigma might differ from our study participants. One important
10 strength of this study is the use of FGDs that allowed the participant's to build on the ideas of
11 their colleagues which added some details to the data.
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15 16 **Conclusion**

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

37 HBV- Hepatitis B Virus; PWHB- People with Hepatitis B; HCPs – Healthcare Providers; IDI
38 – In-depth Interviews; FGDs – Focus Group Discussions
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42 No funding
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46 **Availability of data and materials:** Participants have consented for anonymised transcripts to
47 be shared upon request.
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50 **Authors Contribution:** CAA conceptualised the study. CAA, SES, RACR, FN designed the
51 study. Interview guide was designed by CAA and SES. Data analysis was done by CAA and
52 SES. Manuscript was critically reviewed by SES, FN, RACR. All authors read and approved
53 the manuscript.
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56 **Competing interests:** The authors declare no conflict of interest in this study.

57 **Consent for publication:** Not applicable
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60 **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.

References

1. Schweitzer A, Horn J, Mikolajczyk RT, *et al.* Estimations of worldwide prevalence of chronic hepatitis B virus infection: A systematic review of data published between 1965 and 2013. *Lancet* 2015;386:1546–55. doi:10.1016/S0140-6736(15)61412-X
2. WHO. Hepatitis B Fact Sheet. 2018a. [Retrieved from: <http://www.who.int/mediacentre/factsheets/fs204/en/>. Available on February 06, 2018]
3. Ofori-Asenso R, Agyeman AA. Hepatitis B in Ghana: a systematic review & meta-analysis of prevalence studies (1995-2015). *BMC Infect Dis* 2016;16:130. doi:10.1186/s12879-016-1467-5
4. Musa BM, Bussell S, Borodo MM, *et al.* Prevalence of hepatitis B virus infection in Nigeria, 2000-2013: a systematic review and meta-analysis. *Niger J clin Pr* 2015;18:163–72. doi:10.4103/1119-3077.151035
5. Kolou M, Katawa G, Salou M, *et al.* High Prevalence of Hepatitis B Virus Infection in the Age Range of 20-39 Years Old Individuals in Lome. 2015;:1–7. doi:10.2174/1874357901710011001
6. Bigna JJ, Amougou MA, Asangbeh SL, *et al.* Seroprevalence of hepatitis B virus infection in Cameroon : a systematic review and meta-analysis. 2017;:1–12. doi:10.1136/bmjopen-2016-015298
7. Rufai T, Mutocheluh M, Kwarteng K, *et al.* The prevalence of hepatitis B virus E antigen among Ghanaian blood donors. *Pan Afr Med J* 2014;17:53. doi:10.11604/pamj.2014.17.53.3390
8. Mutocheluh M, Owusu M, Kwofie TB, *et al.* Risk factors associated with hepatitis B exposure and the reliability of five rapid kits commonly used for screening blood donors in Ghana. *BMC Res Notes* 2014;7:1–8. doi:10.1186/1756-0500-7-8739.
9. Sagoe KWC, Agyei AA, Ziga F, Lartey M, Adiku TK, Seshi M, Arens MQ, Mingle J A A. Prevalence and Impact of Hepatitis B and C Virus Co-Infections in Antiretroviral Treatment Naive Patients with HIV Infection at a Major Treatment Center in Ghana. *Journal of Medical Virology* 2012; 84: 6-10

10. Adjei AA, Armah HB, Gbagbo F, *et al.* Correlates of HIV, HBV, HCV and syphilis infections among prison inmates and officers in Ghana: A national multicenter study. *BMC Infect Dis* 2008;**8**:1–12. doi:10.1186/1471-2334-8-33
11. Candotti D, Danso K, Allain J-P. Maternofetal transmission of hepatitis B virus genotype E in Ghana, west Africa. *J Gen Virol* 2007;**88**:2686–95. doi:10.1099/vir.0.83102-0
12. Cho Y, Bonsu G, Akoto-Ampaw A, *et al.* The prevalence and risk factors for hepatitis B surface Ag positivity in pregnant women in eastern region of Ghana. *Gut Liver* 2012;**6**:235–40. doi:10.5009/gnl.2012.6.2.235
13. Trépo C, Chan HLY, Lok A. Hepatitis B virus infection. *Lancet* 2014;**6736**:1–11. doi:10.1016/S0140-6736(14)60220-8
14. Giles-Vernick T, Hejoaka F, Sanou A, Shimakawa Y, Bamba I, Traoré A. Barriers to Linkage to Care for Hepatitis B Virus Infection: A Qualitative Analysis in Burkina Faso, West Africa. *Am J Trop Med Hyg* 2016;**95**:1368–75. doi:10.4269/ajtmh.16-0398
15. Lemoine M, Eholié S, Lacombe K. Reducing the neglected burden of viral hepatitis in Africa: Strategies for a global approach. *J Hepatol* 2015;**62**:469–76. doi:10.1016/j.jhep.2014.10.008
16. Nwokediuko SC. Chronic Hepatitis B : Management Challenges in Resource-Poor Coun- tries. 2011;**11**:786–93. doi:10.5812/kowsar.1735143X.757
17. Butt G, Paterson BL, McGuinness LK. Living with the stigma of hepatitis C. *West J Nurs Res* 2008;**30**:204–21. doi:10.1177/0193945907302771
18. Sandelowski, M., Lambe, C., & Barroso, J. (2004). Stigma in HIV-Positive Women. *J Nurs Scholarsh.*, 2004;36 (2):122-8
19. Stutterheim SE, Bos AER, Shiripinda I, *et al.* HIV-related stigma in African and Afro-Caribbean communities in the Netherlands : Manifestations , consequences , and coping. *Psychol Health* 2012;**27**:1–32. doi:10.1080/08870446.2011.585426
20. Colombini M, Mutemwa R, Kivunaga J, *et al.* Experiences of stigma among women living with HIV attending sexual and reproductive health services in Kenya : a qualitative study. 2014:1–9.
21. Courtwright A, Turner NA. Tuberculosis and Stigmatization :Pathways and Interventions. *Public Health Reports* 2010;**125**:34–42.

- 1
2
3 22. Miller C, Huston J, Samu L, *et al.* ‘ It makes the patient’s spirit weaker’: tuberculosis
4 stigma and gender interaction in Dar es Salaam , Tanzania. *Int. J Tuberc Lung Dis*
5 2017;**21**:42–9.
6
7
8 23. Cotler SJ, Cotler S, Xie H, *et al.* Characterizing hepatitis B stigma in Chinese
9 immigrants. *J Viral Hepat* 2012;**19**:147–52. doi:10.1111/j.1365-2893.2011.01462.x
10
11
12 24. Ellard, J. & Wallace J. (2013). Stigma and discrimination and hepatitis B: A review
13 of current research. *ARCSHS Monographs Series*, 93
14
15
16 25. Ng CJ, Low WY, Wong LP, *et al.* Uncovering the experiences and needs of patients
17 with chronic hepatitis B infection at diagnosis: a qualitative study. *Asia Pac J Public*
18 *Health* 2013;**25**:32–40. doi:10.1177/1010539511413258
19
20
21 26. Wu H, Yim C, Chan A, *et al.* Sociocultural factors that potentially affect the
22 institution of prevention and treatment strategies for hepatitis B in Chinese Canadians.
23 *Can J Gastroenterol* 2009;**23**:31–6.
24
25
26 27. Alizadeh a HM, Ranjbar M, Yadollahzadeh M. Patient concerns regarding chronic
27 hepatitis B and C infection. 2008;**14**:1142–8.
28
29
30 28. Guirgis M, Nusair F, Bu YM, *et al.* Barriers faced by migrants in accessing healthcare
31 for viral hepatitis infection. *Intern Med J* 2012;**42**:491–6. doi:10.1111/j.1445-
32 5994.2011.02647.x
33
34
35 29. WHO. “My untold story”- a hepatitis B patient in Ghana shares his
36 experience. 2018b. [Retrieved from: [http://www.who.int/hepatitis/news-](http://www.who.int/hepatitis/news-events/ghana-pr-an_untold_story/en/)
37 [events/ghana-pr-an_untold_story/en/](http://www.who.int/hepatitis/news-events/ghana-pr-an_untold_story/en/). Available on February 20, 2018]
38
39
40 30. Goffman, E. (1963). Stigma: notes on the management of social spoiled identity.
41 *Eaglewood Cliffs, NJ@ Prentice-Hall.*
42
43
44 31. Link B, Phelan J. Stigma power. *Soc. Sci. Med.* 2014; 103: 24-
45 doi:10.1016/j.socscimed.2013.07.035
46
47
48 32. Li D, Tang T, Patterson M, *et al.* The impact of hepatitis B knowledge and stigma on
49 screening in Canadian Chinese persons. 2012;**26**:597–602.
50
51
52 33. Rafique I, Saqib MAN, Siddiqui S, *et al.* Experiences of stigma among hepatitis B and
53 C patients in Rawalpindi and Islamabad, Pakistan/Expériences de stigmatisation chez
54 des patients atteints d’hépatite B et C à Rawalpindi et Islamabad (Pakistan). *East*
55 *Mediterr Heal J* 2014;**20**:796.
56
57
58
59
60

- 1
2
3
4
5
6
7
8
9
10
11
12
13
14
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41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60
34. Adjei CA, Naab F, Donkor ES. Beyond the diagnosis: a qualitative exploration of the experiences of persons with hepatitis B in the Accra Metropolis, Ghana. *BMJ Open* 2017;**7**:e017665. doi:10.1136/bmjopen-2017-017665
35. Yoo GJ, Fang T, Zola J, *et al.* Destigmatizing hepatitis B in the Asian American community: Lessons learned from the San Francisco Hep B free campaign. *J Cancer Educ* 2012;**27**:138–44. doi:10.1007/s13187-011-0252-9
36. Huang J, Guan ML, Balch J, *et al.* Survey of hepatitis B knowledge and stigma among chronically infected patients and uninfected persons in Beijing, China. *Liver Int* 2016;**36**:1595–603. doi:10.1111/liv.13168
37. Carabez RM, Swanner JA, Yoo GJ, *et al.* Knowledge and fears among Asian Americans chronically infected with hepatitis B. *J Cancer Educ* 2014;**29**:522–8. doi:10.1007/s13187-013-0585-7
38. Wada K, Smith DR, Ishimaru T. Reluctance to care for patients with HIV or hepatitis B / C in Japan. *BMC Pregnancy Childbirth* 2016;**16**:1–6. doi:10.1186/s12884-016-0822-2
39. Dehkordi AH, Mohammadi N, NikbakhatNasrabadi A. Hepatitis-related stigma in chronic patients: A qualitative study. *Appl Nurs Res* 2016;**29**:206–10. doi:10.1016/j.apnr.2015.04.010
40. Lee H, Fawcett J, Yang JH, *et al.* Correlates of Hepatitis B Virus Health-Related Behaviors of Korean Americans : A Situation-Specific Nursing Theory. 2012;**31**:5–22. doi:10.1111/j.1547-5069.2012.01468.x
41. Shi J, Chyun D a., Sun Z, *et al.* Assessing the stigma toward chronic carriers of hepatitis B virus: development and validation of a Chinese college students' stigma scale. *J Appl Soc Psychol* 2013;**43**:E46–55. doi:10.1111/jasp.12040
42. Mohamed R, Ng CJ, Tong WT, *et al.* Knowledge, attitudes and practices among people with chronic hepatitis B attending a hepatology clinic in Malaysia: a cross sectional study. *BMC Public Health* 2012;**12**:601. doi:10.1186/1471-2458-12-601
43. Wallace J, McNally S, Richmond J, *et al.* Managing chronic hepatitis B: A qualitative study exploring the perspectives of people living with chronic hepatitis B in Australia. *BMC Res Notes* 2011;**4**:45. doi:10.1186/1756-0500-4-45
44. Spearman CW, Afihene M, Ally R, *et al.* Hepatitis B in sub-Saharan Africa: strategies to achieve the 2030 elimination targets. *Lancet Gastroenterol Hepatol* 2017;**2**:2121. doi:10.1016/S2468-1253(17)30295-9
45. Labaree RV. Organising your Social sciences Research Paper: Types of Research designs. 2009.[Retrieved from: <http://libguides.usc.edu/writingguide/researchdesigns>. Availabe on January 25, 2018]
46. Ghana Statistical Service. Ghana Health Service (GHS), and ICF Macro.

- 1
2
3 Ghana Demographic and Health Survey 2008, Calverton, Maryland, USA: GSS, GHS,
4 and Macro International. 2009
5
6
7 47. Ghana Statistical Service. 2010 population projected by sex, 2010-2016. 2016.
8 Retrieved from: http://www.statsghana.gov.gh/pop_stats.html, Accessed on May 24,
9 2018]
- 10
11 48. Ministry of Health. Category: Ministry agencies. 2018. [Retrieved from:
12 <http://www.moh.gov.gh/category/ministry-agencies/>, Accessed on January 01, 2017]
- 13
14 49. Carter N, Bryant-Lukosius D, DiCenso A, *et al.* The Use of Triangulation in
15 Qualitative Research. *Oncol Nurs Forum* 2014;**41**:545–7. doi:10.1188/14.ONF.545-
16 547
- 17
18
19 50. Etikan I, Musa SA, Alkassim RS. Comparison of Convenience Sampling and
20 Purposive Sampling. 2016;**5**:1–4. doi:10.11648/j.ajtas.20160501.1
- 21
22 51. Palinkas L a, Horwitz SM, Green C a, *et al.* Purposeful Sampling for Qualitative
23 Data Collection and Analysis in Mixed Method Implementation Research. *Adm Policy*
24 *Ment Heal* 2015;**42**:533–44. doi:10.1007/s10488-013-0528-y.Purposeful
- 25
26
27 52. Polit DF, Beck CT. Nursing research: Principles and methods (8TH
28 Edition). 2014. Lippincot William & Wilkins.
- 29
30 53. Wellings K, Branigan P, Mitchell K. Discomfort, discord and discontinuity as data:
31 Using focus groups to research sensitive topics. *Cult Heal Sex* 2000;**2**:255–67.
32 doi:10.1080/136910500422241
- 33
34 54. Valizadeh L, Zamanzadeh V, Bayani M, Zabihi A. The Social Stigma Experience in
35 Patients With Hepatitis B Infection. *Gastroenterol Nurs* [Internet]. 2017;**40**(2):143–
36 50. Available from: [http://insights.ovid.com/crossref?an=00001610-201703000-
37 00009](http://insights.ovid.com/crossref?an=00001610-201703000-00009)
- 38
39 55. Vaismoradi M, Turunen H, Bondas T. Content analysis and thematic analysis:
40 Implications for conducting a qualitative descriptive study. *Nurs Heal Sci*.
41 2013;**15**(3):398–405.
- 42
43 56. Eguchi H, Wada K. Knowledge of HBV and HCV and Individuals' Attitudes
44 Toward HBV- and HCV-Infected Colleagues: A National Cross-Sectional Study
45 among a Working Population in Japan. *PLoS One* 2013;**8**:1–7.
46 doi:10.1371/journal.pone.0076921
- 47
48 57. Dahl TFM, Cowie BC, Biggs B, *et al.* Health literacy in patients with chronic hepatitis
49 B attending a tertiary hospital in Melbourne : a questionnaire based survey. 2014;:1–9.
- 50
51 58. Dam L, Cheng A, Tran P, *et al.* Hepatitis B stigma and knowledge among
52 Vietnamese in Ho Chi Minh City and Chicago. *Can J Gastroenterol Hepatol*
53 2016;**2016**. doi:10.1155/2016/1910292
- 54
55
56
57
58
59
60

- 1
2
3 59. Kan Q, Wen J, Xue R. Discrimination against people with hepatitis B in China. *Lancet* 2015;**386**:245–6. doi:10.1016/S0140-6736(15)61276-4
4
5
6
7
8 60. Ochu CL, Beynon CM. Hepatitis B vaccination coverage, knowledge and
9 sociodemographic determinants of uptake in high risk public safety workers in
10 Kaduna State, Nigeria: A cross sectional survey. *BMJ Open* 2017;**7**:1–10.
11 doi:10.1136/bmjopen-2017-015845
12
13 61. Schillie S, Vellozzi C, Reingold A, Harris A, Haber P, Ward JW,
14 Nelson NP. Prevention of hepatitis B virus infection in the United States:
15 Recommendations of the Advisory Committee on Immunisation Practices. MMWR
16 Report. 2018. [Retrieved from
17 <https://www.cdc.gov/mmwr/volumes/67/rr/rr6701a1.htm>. Available on February 20,
18 2018]
19
20
21 62. Hajarizadeh B, Wallace J, Richmond J, *et al*. Hepatitis B knowledge and
22 associated
23 factors among people with chronic hepatitis B. *Aust N Z J Public Health*
24 2015;**39**:563–8. doi:10.1111/1753-6405.12378
25
26
27 63. Upadhyaya N, Chang R, Davis C, *et al*. Chronic hepatitis B: Perceptions in Asian
28 American communities and diagnosis and management practices among primary care
29 physicians. *Postgrad Med* 2010;**122**:165–75. doi:10.3810/pgm.2010.09.2213
30
31
32 64. Hamdiui N, Stein ML, Timen A, Timmermans D, Wong A, van den Muijsenbergh
33 METC, *et al*. Hepatitis B in Moroccan-Dutch: A quantitative study into determinants
34 of screening participation. *BMC Med*. 2018;**16**(1):1–6.
35
36
37 65. WHO. Guidelines for the prevention, care and treatment of persons with chronic
38 hepatitis B infection. 2015;:166.
39
40 66. Adjei CA, Atibila F, Apiribu F, Ahordzor F, Attafuah PA, Ansah-Nyarko M,
41 Asamoah R, and Menkah W. Hepatitis B infection among parturient women in Peri-
42 Urban Ghana. *American Journal of Tropical Medicine and Hygiene*. 2018;
43 Doi:10.4269/ajtmh.17-0752.
44
45
46 67. Yang T, Wu MC. Discrimination against hepatitis B carriers in China. *Lancet*
47 2011;**378**:1059. doi:10.1016/S0140-6736(11)61460-8
48
49
50 68. Yu L, Wang J, Zhu D, *et al*. Hepatitis B-related knowledge and vaccination in
51 association with discrimination against hepatitis B in rural China. *Hum Vaccines*
52 *Immunother* 2016;**12**:70–6. doi:10.1080/21645515.2015.1069932
53
54
55 69. Eldredge LKB, Markham CM, Ruiters RAC, Fernández MA, Kok G,
56 Parcel GS. *Planning Health Promotion Programmes: An Intervention Mapping*
57 *Approach (4th Edition)*. 2016. Jossey-Bass
58
59
60

70. Setlhare V, Wright A, Couper I. The experiences of people living with HIV/AIDS in Gaborone, Botswana: stigma, its consequences and coping mechanisms. *South African Fam Pract* [Internet]. 2014;56(6):309–13. Available from: <http://www.tandfonline.com/doi/abs/10.1080/20786190.2014.975484>

71. Ma PHX, Chan ZCY, Loke AY. Self-Stigma Reduction Interventions for People Living with HIV/AIDS and Their Families: A Systematic Review [Internet]. *AIDS and Behavior*. Springer US; 2018. Available from: <https://doi.org/10.1007/s10461-018-2304-1>

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			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the interview or focus group?	
Duration	21	What was the duration of the interviews or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

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

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.