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Barriers to accessing hepatitis B medication: a qualitative study from the USA and Canada

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ABSTRACT

Objectives To collect and document the numerous barriers that people living with hepatitis B (PLHB) encounter when trying to access their hepatitis B virus (HBV) medications.

Design Researchers collected qualitative data through 24 online interviews. The semistructured interview questions focused on the impact that HBV has on different aspects of daily life (physical, emotional and social), personal experiences managing their infection, HBV treatment experiences and interactions with healthcare providers.

Setting All interviews occurred over Zoom.

Participants The participant cohort consisted of 12 males and 12 females. 63% of all participants represented communities of colour (37% white, 17% black/African/African American and 46% Asian/Asian American). Most of the participants were on antiviral treatment at the time of the study (62%). Participants were PLHB (self-reported), ≥18 years old, living in the USA or Canada and spoke English.

Results Participants reported several barriers to accessing medicine among PLHB including financial barriers, health insurance and pharmacy preauthorisation process and other intangible barriers like lack of access to reliable patient-friendly information and stigma. The identified barriers to accessing HBV medication impacted patients' continuity of care.

Conclusions Access to medicine is essential to improving health outcomes. PLHB experience significant barriers to accessing HBV antivirals at different levels. Patient-related, physician-related and healthcare system barriers were identified as themes contributing to antiviral access challenges. More research is needed to identify strategies to improve access to HBV medications.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ The qualitative data collected provided a comprehensive view of the core barriers to accessing antivirals in the USA and Canada.
- ⇒ The study's data collection via Zoom allowed researchers to maintain patient privacy and provide convenience for study participants.
- ⇒ The study was conducted only in English, which limited who was able to participate.
- ⇒ The study had a small sample size of participants only living in the USA and Canada, and the results cannot be reflective of global barriers to accessing hepatitis B virus antivirals.

BACKGROUND

Approximately 296 million people are living with chronic hepatitis B virus (HBV) globally, with nearly 2.4 million living in the USA.[1 2] It is estimated that nearly two-thirds of chronically infected individuals in the USA are undiagnosed.[3 4] Based on current treatment guidelines, approximately 20%–40% of people living with hepatitis B (PLHB) meet criteria for treatment with antiviral therapy,[5] however, it is estimated that less than 10% of individuals eligible for treatment receive the recommended treatment.[6 7] Antivirals for HBV are highly effective at preventing and delaying serious liver damage and improving the quality of life for PLHB. Approximately one in four untreated chronic HBV infections will result in premature death from significant liver complications such as cirrhosis, liver failure or hepatocellular carcinoma (liver cancer).[8 9]

Barriers to access to care and medicine are numerous and often indicate underlying socioeconomic disparities. Barriers to medication access could be classified as patient-related barriers, physician-related barriers and healthcare system-related barriers.[10] Studies focused on people with chronic illnesses have shown that interrupted access to medicine has a detrimental effect on patients' health outcomes.[11 12] A study looking at barriers to accessing medicine among those living with HIV/AIDS explained a lack of awareness about the importance of treatment.[13] People living with hepatitis C also experienced similar barriers, such as a lack of patient-tailored messaging that focused on their unique needs.[14] Other studies emphasised the impact of inadequate physician communication and messaging about the recommended treatment,[15] and limited availability of health insurance coverage resulting in out-of-pocket (OOP) payments for medicine.[16]

There is limited research on medication access barriers for PLHB. Additionally, emphasis has been placed on tangible barriers such as health insurance, and cost and availability of medication. HBV is a unique disease impacted by stigma, discrimination[17 18] and disease-related knowledge gaps.[19] These challenges create another layer of intangible barriers to accessing medicine that is less explored and not well documented.

This paper aims to highlight psychosocial, systemic and financial barriers to accessing medicine for HBV as reported by the people living with the disease.

METHODS

Study design

This study employed a qualitative approach. Qualitative data were collective via Zoom interviews with PLHB.

Participant recruitment

Potential interview participants were recruited via purposive sampling to ensure that we reached PLHB. The invitation to participate was sent to potential participants via organisational e-newsletters, social media (reaching ~45 000) and at the end of an online survey, which was conducted as part of a larger study.[20] Eligibility criteria for the interviews were age (≥18 years old), living with chronic HBV (self-reported), living in the USA or Canada and being able to communicate in English.

Data collection

A qualitative, semistructured interview guide was developed and reviewed by a panel of experts, which included a PLHB (online supplemental appendix 1). Interview questions focused on the impact HBV has on different aspects of daily life (physical, emotional and social), personal experiences managing HBV, HBV treatment experiences and interactions with healthcare providers. Each interview lasted 60–90 min and all were conducted between February 2020 and May 2020. All interviews were conducted by the same interviewer, who is a qualified public health researcher and is familiar with HBV. A total of 24 Zoom interviews were conducted. Interviews were concluded when saturation of themes was reached.

Data analysis

Interviews were recorded via Zoom and transcribed by a professional transcription service. The resulting transcripts were analysed using a direct content analysis approach to develop a codebook that guided the organisation of codes (online supplemental appendix 2). Each code was clearly defined to ensure coding accuracy and improve intercoder reliability (ICR). The codebook was a living document, as the team met regularly to discuss emerging themes from the data. A team of five trained researchers coded the interviews using Dedoose qualitative analysis software (V.8.3.45).[21] Each interview transcript was coded independently by two trained researchers. ICR was assessed using Dedoose ICR calculation tool for each interview (ICR ranged from 65% to 75%). Both coders reviewed discrepancies in an open discussion until an agreement was reached.

Patient and public involvement

Patient experts were consulted in the creation of the interview semistructured guide. Patients reviewed the study tools and provided input on the language used and the understandability and comprehension of the questions. Some interview participants and other patient experts were asked to participate in the development of the manuscript. At this time, there are no plans to ask patients to aid in disseminating the study results, though they may choose to share it within their networks.

RESULTS

The participant cohort consisted of 12 males and 12 females. 63% of all participants represented communities of colour (37% white, 17% black/African/African American and 46% Asian/Asian American). Most of the participants were on antiviral treatment at the time of the study (62%). Interview participants shared multiple factors (patient-related, physician-related, healthcare system) that affected their access to HBV care and medicine. Some of these factors have long been known to impact access to healthcare and access to medicine across different diseases while others are unique to the experiences of PLHB.

Patient-related barriers

Stigma

Participants repeatedly mentioned how HBV-related stigma has affected their care seeking behaviour, and access to medication. One participant expressed how her fear of stigma affected her ability to seek information and learn about the benefits of medications through patient-peer education. '*[I wonder] 'how long have people been on this [medication]?… I feel very alone about this. I don't know anybody else that has HBV. So, it's not like there's a bunch of people with diabetes or some other chronic disease. There isn't anybody that I know that has it or that talks about it because it's such a stigma. I'm not going to put it on Facebook, like everybody does with all their fun diseases.*' [*Female, 44 y/o*]

Another participant explained how his previous childhood experience with HBV-related stigma led him to forego seeking care as an adult. '*It affected me for a long time. I didn't seek treatment. I probably wouldn't seek treatment for several factors. The main factor, even if I had insurance, was that I wasn't feeling a lot of symptoms at the time. But the biggest reason is the stigma that I suffered as a kid. So, I was very fearful for a number of years, but within the last five years I came to terms with it.' [Male, 41 y/o]*

HBV knowledge gaps and lack of access to information

A lack of access to information about HBV and its treatment was also identified as a barrier to initiating HBV treatment by respondents. Participants expressed feeling as though they are not knowledgeable enough about HBV to make a decision regarding their own treatment.

One interview participant noted that a lack of accessible patient-friendly information hindered their understanding of medication options: '*I'm not a doctor…When I see research on HBV that's been published, a lot of it is way above my pay grade. The medical terminology and how things are discussed, I really don't understand it. It seems like they [the doctors] do because that's what they went to school for… It's a bit frustrating that when you try and do the research … it's not written in plain English. It's very medical based…there's a need for more information and knowledge that is directly available to the general public…*' *[Female, 44 y/o]*

Another participant described his inability to make an informed decision about starting treatment. Despite his efforts to be more active in making decisions about his health, he felt as though he had to blindly trust the doctor's suggestions: '… *it came to the point that I had to agree, because they [the doctor] went to school. But even though my viral DNA wasn't high, I had to adhere to what he said. It's the lack of awareness … I wish to understand [how] the medication works with the virus, how the medication reduces the virus… how long shall I take the medication? Are there any chances of me developing immunity while taking the medication? Is there any chance of me losing the cccDNA?*' (Covalently closed circular DNA (cccDNA) is the transcriptional template of the HBV, allowing the virus to continuously copy itself. The persistence of cccDNA in liver cells is a significant barrier to curing hepatitis B and puts an individual at risk of hepatitis B reactivation under certain medical circumstances.) *[Male, 26 y/o]*

Physician-related barriers

Interview participants found it difficult to learn more about HBV treatment and how it would specifically affect them due to poor communication with their physician.

Physician communication

Interview participants felt as if their concerns about the HBV medications that they were taking were being dismissed: '*The treatment caused so much havoc in my life and nobody's ever explained that to me because my liver specialist is not a very communicating person. I would tell [my liver specialist] about the pain that I was going through every time I went. He'd either blow it off, or he'd prescribe me some new pain medication or a motility drug or something…His explanation would be, 'It's your liver, it's your hepatitis, it's your cirrhosis.'* *[Male, 50 y/o]*

Others mentioned that the lack of clear communication about the meaning of their test results and the side effects of the medication made it difficult to understand the importance of beginning treatment. One interviewee said: '*[My doctor said] 'Well, you need to be on Vemlidy.'… And I've researched Vemlidy and it's like, 'Okay.' If I go on this drug, I can't go off of this drug. I don't think my viral load is so high that it needs to be brought down right now…Nobody is very [communicative]. They always just say, 'You're good.' And they give me the results and it's always like 'it's [test results] normal if it's between this and this'… It [HBV] doesn't seem like it's something that needs to be treated.*' *[Female, 44 y/o]*

Healthcare system barriers

Interview participants identified systemic issues such as OOP spending, coverage of HBV medication by insurance and challenges with specialty pharmacies and obtaining prior authorisations as significant barriers.

Cost of HBV medication

Interview participants, regardless of their insurance status or type of insurance coverage, reported the cost of medication as a major challenge for them. One participant, who is under Medicare, described how his co-pay amounts throughout the year. '*It [medication] is expensive even with insurance. You know on Medicare I have a [prescription] supplement. I just picked up my 90-day supply of my drug [and paid] $1100 out of my pocket with a Medicare supplement. Next 90-day will be about $895. So, by the time the year ends, it will be quite a few thousand bucks. So, what I'm saying is the virus has been expensive for me, even though I've had top-notch insurance before I retired.*' *[Male, 70 y/o]*

Another interview participant described how his one-income family, despite insurance coverage, could not afford his medication. '*We were covered under her [my wife's] insurance, but we couldn't afford the type of policies that would cover for [HBV] medication that we used to have access to. Consequently, the screenings, the test that was needed for my health were out-of-pocket and as far as the medication, I couldn't afford it. So, without telling my wife about it, I just stopped taking it. I remember I was quoted a price of somewhere around…$2500 to $3000 a month.*' *[Male, 52 y/o]*

Insurance challenges

Interview participants also reported challenges with prescription coverage, including how choosing the wrong supplement plan may lead to a high co-pay. '*I'm on Medicare and the cost has gone up, because of the prescription drug process. That has been a bit of a challenge, because you really have to dig in and make sure that it's covered by the prescription drug coverage that you choose, otherwise it was going to be almost the full price, which is prohibitively expensive.*' *[Male, 65 y/o]*

Another participant explained how his prescription plan changed their coverage of a first line HBV treatment, making it more challenging for him to obtain his medication. '*About late last year, they stopped supporting [drug A], and they were making it more difficult to get authorization. So, I had to go back to [drug B]. And now I think they have it back on the list, … and it seems like they switch in and out of supporting [drug A] and they prefer you to take the generic form of [drug B].*' *[Male, 47 y/o]*

Pharmacy challenges

Some participants reported challenges accessing their HBV medication through pharmacies. The issues reported were either administrative or insurance related.

One interview participant said: '*I had to switch specialty pharmacies because of my health care coverage. For some reason, one pharmacy that used to accept it doesn't accept it anymore, so we switched, and it seems to be okay for now.' [Female, 46 y/o]*

Another interview participant highlighted that living in a rural area may have contributed to the issues he initially faced with the pharmacy. '*I live in a rural area, in a small community. The only problem I have sometimes is that the pharmacy sometimes doesn't have it. I might be the only one in our community who has it [HBV].' [Male, 41 y/o]*

DISCUSSION

This qualitative study identified patient-related, physician-related and healthcare system-related barriers preventing PLHB in the USA and Canada from accessing their medications. The results of the study highlight the complex interactions between psychosocial and systemic factors and the role they play in individuals' health outcomes.

Patient-related barriers

Barriers such as stigma have been extensively documented as negatively impacting medication access and adherence to treatment for diseases similar to HBV, such as HIV.[22] Studies have demonstrated that people living with chronic illnesses often express feeling a need to keep their disease hidden, which can result in a lack of peer and familial support.[23] This is further supported by data in this study, in which interviewees described the social pressures of living with a chronic, stigmatised illness with low community level awareness as a barrier to seeking more information about treatment. This impacts their health seeking behaviour like attempting to learn more about what medications are available.

There is a noticeable gap in research studying the relationship between access to patient-friendly information and a person's understanding of their treatment options. The few available studies across the spectrum of diseases confirm that the inaccessibility of disease-specific information can lead to a gap in treatment access.[19] Interview participants in our study highlighted a strong desire to better comprehend the different medications available, and how the different choices would impact them. Despite doing their own research, there was limited information that contained the answers they sought, such as how the medication interacted with the virus. The information they did find was often wrapped in medical jargon and difficult for a patient to fully comprehend. Thus, participants did not feel as though they were equal decision-makers and voiced a strong desire to be involved in decisions relating to their treatment.

Physician-related barriers

Clear communication between physicians and patients is also critical to ensuring that individuals understand the importance of disease management.[24] This understanding, or lack thereof, affects patients' adherence to medications.[15 16] Previous studies show that patients living with chronic illnesses who receive comprehensive communication from their doctors were more likely to begin and adhere to treatment regimens.[15 16] Participants in this study who experienced poor communication from their doctors reported that it affected their perceptions about the necessity of treatment and its benefits.

Healthcare system barriers

The availability and adequacy of insurance coverage are cornerstones to healthcare. In the USA, where the healthcare system is fragmented and difficult to navigate,[25] the lack of health insurance, underinsurance and OPP add a layer of complexity leading to poorer health outcomes.[11 26] Interview participants reported that health insurance coverage influenced their ability to access treatments. Those who lacked adequate insurance coverage were frequently forced to stop their prescribed HBV medication, often due to cost barriers. OOP payments for medicine have also been a well-documented barrier to accessing medicines.[16 27] Interview participants who reported having to pay a high copay relative to their income, said that co-pays have been a challenge to adhere to their antiviral therapy and regular follow-up testing. Although all interview participants who mentioned OOP payments as a challenge had health insurance coverage, it was clear that their OOP share remained a challenge that led to interruptions in the continuum of medication.

The pharmacy prior authorisation process has been criticised by healthcare providers and patients for its negative impact on patients' timely care and health outcomes.[28 29] Our study shows that despite the need for their prescribed antivirals, the pharmacy prior authorisation process has led to interruptions in patients' supply of medication. This unmonitored and unplanned cessation of treatment poses serious health threats such as flares and consequent liver damage and cirrhosis.[30]

The location of residence also impacts the continuity of care. Studies have shown that pharmacies located in rural areas are more likely to have drug shortages.[31] In our study, those living in rural communities faced challenges maintaining a continuous supply of antiviral medication due to stocking issues by their pharmacies.

Additionally, it is important to note that the intersectionality of the barriers reported by interview participants create complex circumstances for PLHB. For example, those who reported the lack of adequate communication from their healthcare providers were also subject to scarcity in reliable sources for credible information. This is further compounded by difficulty asking questions about HBV due to misconceptions and stigma. The complicated connectedness of these issues contributed to patients' frustration and limited their ability to access their treatment.

LIMITATIONS

Our study has several limitations. While the study is qualitative in nature and authors made their best effort to ensure data saturation was reached, the study had a small sample size of participants living in the USA. Experiences may not be generalisable to the broad and diverse population of people living with HBV.

Recruitment for interviews and the interviews themselves were all done in English language which might limit the population sample of PLHB as it is an extremely diverse and multilingual community. Additional research is needed to continue to understand the full-lived experience of HBV and work towards identifying and addressing barriers to accessing care and medication.

CONCLUSION

Previous studies show that access to medicine has been essential to improving health outcomes for people living with chronic illnesses and that those with interrupted access to medicine were more likely to experience worse outcomes. Our study documents the various levels of barriers that PLHB in the US and Canada face to access their medications, such as stigma, lack of information around treatment options, poor physician communication, cost of the antiviral medication and insurance coverage. More studies are needed in this area to explore strategies to mitigate these barriers and improve medication access and health outcomes of PLHB.

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Contributors YI: writing–original draft, concept development, conducting interviews, interview coding (has access to the data), formal analysis, guarantor. MJ: writing–original draft, concept development, interview coding, formal analysis. CC: review and editing, interview coding (has access to the data). BZ: interview coding, review and editing. CF: interview coding, review and editing. SJ: review and editing. All authors contributed to the interpretation of the results and critically revised the paper. All authors read and approved the final manuscript.

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Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by Heartland Institutional Review Board: HIRB Project No. 191221-270. Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

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