

 **HEP
CAN'T
WAIT!**

**THE IMPACT OF
STIGMA AND
DISCRIMINATION
AFFECTING
PEOPLE WITH
HEPATITIS B**



**World
Hepatitis
Alliance**

**WITH THANKS TO OUR
ADVISORY GROUP:**

Dr Chari Cohen

Catherine Freeland

Maureen Kamischke

Chris Munoz

Capucine Penicaud

Dr Thomas Tu

Dr Jack Wallace

Dr Su Wang

**And all of the participants who
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FOREWORD

The World Health Organization (WHO) estimates that 296 million people worldwide live with hepatitis B, with the virus claiming nearly 900,000 lives every year. The hepatitis B virus attacks the liver and can cause both acute and chronic disease. People living with the virus are at a higher risk of liver cirrhosis and liver cancer. Hepatitis B is the leading cause of liver cancer, the third most deadly cancer.¹

The majority of people living with the virus are unaware that they have the infection, resulting in thousands of lives lost each year despite the availability of treatments that are both effective and affordable in most countries.

Millions of people living with hepatitis B face an added burden of stigma and discrimination. Misunderstandings about how hepatitis B is transmitted can affect people's personal and professional lives, dividing families, splitting communities and restricting opportunities. People living with hepatitis B are often subject to discriminatory policies, which are sometimes disguised as public health interventions, but provide no benefit for people with hepatitis B or their families. These frequently impact their human rights to work, study and travel.



Policy and decision-makers have an essential role in ensuring that anti-discrimination laws, public health policy, education and health systems work together with civil society and the affected communities to tackle the crisis of stigma and discrimination.

In this paper, we shed light on the effects of the stigma and discrimination faced by some people affected by hepatitis B and illustrate the lived experiences of those impacted by the virus.

To address these challenges, we recommend health systems adopt the following policies:

- **Provide accurate and accessible information regarding hepatitis B for those newly diagnosed including transmission, health promotion information, rights and responsibilities, and long-term health plan.**
- **Ensure all newly diagnosed individuals are linked to appropriate and supportive healthcare services for ongoing monitoring and management.**
- **Ensure equitable and affordable access to prevention of mother-to-child transmission (PMTCT) programmes for all women.**

This report highlights the human experiences of stigma and discrimination related to hepatitis B, demonstrating the impact that living with the virus can have on mental health, quality of life, individual freedoms and human rights. We focus on the work of people trying to challenge this stigma and discriminations and describe the support they need to be successful.

- **Ensure that mental and emotional support is provided to people diagnosed with hepatitis B and their families**
- **Require that all healthcare professionals receive ongoing hepatitis education and are aware of stigma and how to address it.**
- **Ensure testing for hepatitis B is conducted in the context of healthcare services, that the results are confidential, that the testing is of direct benefit to the person being tested, and is not required as a condition of employment or education.**
- **Ensure anti-discrimination laws and policies are correctly implemented and that adequate recourse is given to enable people experiencing discrimination to pursue justice through the legal system.**
- **Ensure there are legal protections in place for people with hepatitis B, including protection from government sanctioned discrimination.**
- **Ensure that immigration and visa policies do not limit the freedoms of people living with hepatitis B, because of their diagnosis.**



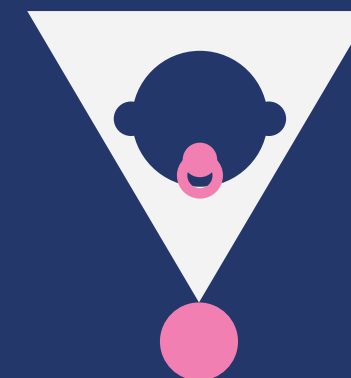
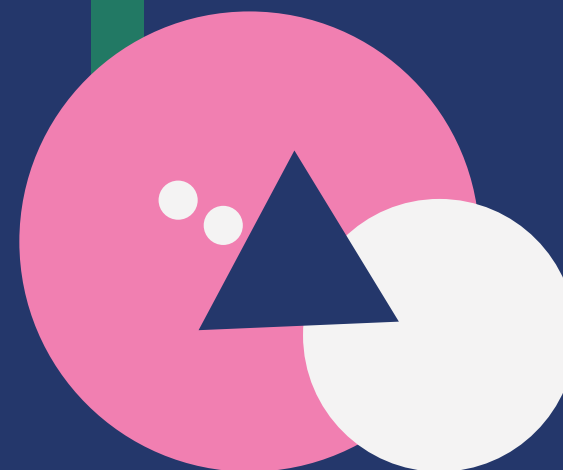
296
million

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Hepatitis B
is a leading
cause of
liver
cancer



Hepatitis B
is most often
transmitted
from mother to
child at birth



The birth
dose vaccine
can prevent
transmission
and is available
for USD 0.20

820
thousand

people die
each year
because of
hepatitis B



Only
43%

of babies worldwide
had access to the
birth dose vaccine



CHAPTER

1

STIGMA AND DISCRIMINATION

Health-related stigma harms individuals, as well as society as a whole. According to 'Health Stigma and Discrimination Framework Research', health-related stigma is a global barrier to health-seeking behaviour, as well as engagement in care and treatment adherence.² Stigma surrounding viral hepatitis is widespread. The 2017 World Hepatitis Alliance Civil Society Survey found that 93% of civil society representatives (from 72 different countries) reported that people living with viral hepatitis in their home country faced some level of stigma and discrimination.³

For those living with communicable diseases, stigma is often rooted in the fear of infection and transmission, misconceptions about how the disease is transmitted and what living with the disease is like, as well societal judgement and blame. People experiencing stigma may adopt these societal beliefs as internalised stigma, which has an impact on their own mental health. In some cases, they might be subject to multiple stigmas based on stereotypes involving their gender, race or religion in what is known as intersecting stigma. Stigma may also negatively impact on their friends and family in the form of associative stigma.⁴ Unlike other infectious diseases, the majority of people with hepatitis

B were infected at birth. The implications of this are that hepatitis B is an infection that can affect multiple members of a family and that this occurs across generations, with stigma in all its forms and discrimination affecting families as a whole.

Stigma and discrimination bars people from fully participating in society.⁵ Stigma becomes discrimination when it becomes formalised in any way; such as being written into law or adopted within the policy and programmes of private or public organisations.⁶ People experiencing communicable diseases stigma, commonly experience wider discrimination as well. This can be in the form of workplace screening procedures or the refusal of housing. Stigma and discrimination bar people from fully participating in society.⁷ Due to widespread stigma and discrimination, people who are living with hepatitis B often experience barriers to accessing health services. Eliminating the stigma surrounding hepatitis through the introduction of policies and structural changes has been named as a key factor in hepatitis elimination by WHO. This includes employment and housing discrimination, as well as the criminalisation of drug use and sex work.⁸



KEY TERMS

Discrimination

Discrimination is the practice of actively subjecting an individual to different treatment or denying services or freedoms to someone based on an identifying feature, including skin colour, sex, sexuality or health status.⁹

Stigma

Stigma is defined as a 'mark', either real or perceived, that sets someone apart from others. It can lead to someone viewing themselves differently or being marked as different. This can affect individuals by being stigmatised by their family, but also make them and their family ostracised by the wider community.¹⁰

Prevention of mother-to-child transmission

Mother to child transmission of hepatitis B is the most common route of transmission globally. Prevention of mother-to-child transmission (PMTCT) of hepatitis B can be done through testing all mothers for hepatitis B, and administering hepatitis B birth dose vaccines to all babies within 24 hours, according to WHO recommendations. The risk of chronic infection is very high with mother-to-child transmission. Approximately 80-90% of children who contracted the virus under the age of five years of age go on to develop a chronic or infection. In comparison, less than 5% of adults who are exposed to the virus will develop a chronic infection.¹¹

Hepatitis B birth dose vaccine

The birth dose is the first dose of the hepatitis B vaccine given within the first 24 hours of birth. Transmission of hepatitis B can be prevented by 95% if the hepatitis B birth dose is administered within the first 24 hours of birth followed by the hepatitis B immunization series.¹²

Hepatitis B treatment

There aren't currently any curative treatments for chronic hepatitis B. However, cost effective treatments allow someone to live a long and healthy life.

Not everyone living with hepatitis B requires treatment. Many people living with hepatitis B have no symptoms and only require regular monitoring. For those that do, WHO has published guidelines recommending the treatment of hepatitis B.¹³

CHAPTER 2 THE PERSONAL IMPACT OF STIGMA

Arafat is a public health worker in a rural part of western Uganda. When Arafat's uncle came to the hospital, he was diagnosed with terminal liver cancer resulting from hepatitis B infection. As well as the trauma of providing palliative care to his uncle, Arafat and his family faced an added burden of stigma and discrimination from the community associated with hepatitis B.



There was a terrible rumour spreading through the community that my uncle's wife caused his death. They blamed some kind of 'witchcraft' which is a very real belief in many communities. The community wanted to stop my uncle's wife from visiting my uncle while on his deathbed.

The family and the community didn't allow my uncle's wife to attend his funeral despite my pleas explaining to them that his death was from hepatitis B.

"My uncle's death wasn't the end of the story," remembers Arafat. "The community decided to take revenge on my uncle's wife, subjecting her to gender-based violent attacks and eventually burning down her home. All the photos of my uncle were in that house and were destroyed in the fire."

Arafat's story is not the only one of its kind. Many communities across the globe have widely held misconceptions about the causes of hepatitis B. Research from Ghana, shows that people living with hepatitis B encounter stigma and discrimination due to the belief that hepatitis B is highly contagious, and falsely transmitted through casual contact and caused by "curses."¹⁴ These findings have also been found in similar research across the world. The research goes on to demonstrate how some people believe illnesses to be consequences of religious sin. Symptoms of hepatitis B, such as jaundice and swelling of ankles or the abdomen are often considered to be "curses"

caused by disrespecting or not taking care of one's parents. In families where these beliefs are widespread, people living with hepatitis B are denied medical care and are instead subjected to rituals to lift the "curse" in religious settings. These dangerous misconceptions are also evident among some undertrained healthcare professionals, who have been found to be performing "cleansing rituals" in various healthcare settings.¹⁵

As demonstrated by Arafat's experience, the impact of these misconceptions on the lives of people living with hepatitis B can be immense. People living with hepatitis B report being stopped from sharing utensils with others, denied participation in group activities and even refused tenancy in student accommodation. In some cases, they report being thrown out of their own homes because their family members fear contracting the virus or attracting the "wrath of god" by being close to someone they believe to be "cursed."¹⁶

The community were trying to erase him from history, all due to their false beliefs. Nobody should have to face what my uncle and his wife faced, especially in his final days. It is unacceptable that stigma can be allowed to spread through communities. Communities should receive accurate educational information about the disease, how it is contracted and how it can be prevented. We cannot allow people to be erased from history. My uncle's name was Masereka Kundi and he should be remembered.

Reducing the stigma surrounding hepatitis B is crucial to improving the quality of life of people living with hepatitis B. This is a difficult task that requires the educating of both communities and healthcare professionals, while also providing people living with hepatitis B with accurate information and support.

False beliefs surrounding hepatitis B are not only common in Africa. Research conducted in the United States, China, Iran, Japan, Australia and the Netherlands revealed each country has its own unique challenges, with misconceptions surrounding hepatitis B even in healthcare settings.¹⁷

Lien found out she was living with hepatitis B during a health screening which was required before accepting a scholarship to a prestigious university. Her diagnosis changed her life path and she has been dedicated to breaking down barriers for people living with hepatitis B ever since.

When I was at college, I secured a scholarship to study at a university in Europe. I felt fortunate and proud, as I was the first person from my small village in Northern Vietnam to get the opportunity to study abroad. As a part of the paperwork for my scholarship, I had to do a health check and a hepatitis B test was on the list. When I came to get the results, the doctor at the health check department told me I had hepatitis B and that I would therefore not be able to go overseas. I did not know about hepatitis B, so I did not question his advice. I blindly trusted him and rejected the scholarship. It was only when I was older that I found out that that doctor was wrong. I could have taken up the scholarship.



Losing my scholarship was not the worst part of my diagnosis. The only thing I knew about hepatitis at the time was that it was a liver disease, as hepatitis in Vietnamese translates to “liver inflammation”. My grandmother passed away due to liver cancer when I was a child and I thought I would die too. I was given no further information about the reality of living with hepatitis B.

Oddly enough, since I had no symptoms, I nearly forgot about my diagnosis. A few years later, I started researching hepatitis B on the internet. At the time, using the internet was a luxury, with one-hour access at an internet cafe costing me as much as one meal. It took me many meals to discover I can live with hepatitis B.

Research shows that many people newly diagnosed with hepatitis B receive minimal information about their diagnosis. Often people do not consent to being tested, do not understand what they are being tested for or what receiving a positive diagnosis can mean. Many people are tested in educational or workplace settings as part of a “health check” and are provided with their diagnosis by non-health professionals. Frequently, after diagnosis, individuals are not adequately informed about how the virus spreads, the long-term progression of the disease and possible complications or treatment options available to them. This lack of information puts those newly diagnosed with hepatitis B under a lot of stress and leaves them unprepared to deal with the burden of a lifelong condition. The lack of counselling available further impedes the burden of diagnosis on their mental health.¹⁸ Support services such as those offered by civil society organisations and peer support can provide individuals with the psychosocial support needed to come to terms with living with hepatitis B, but these services are only sporadically available globally and are often underfunded. The impact of stigma can also prevent people living with hepatitis B from being able to find others with the same condition. This peer support is crucial for newly diagnosed people seeking connection with others, but with so few people willing to share their stories this support can be hard to find.

POLICY RECOMMENDATION

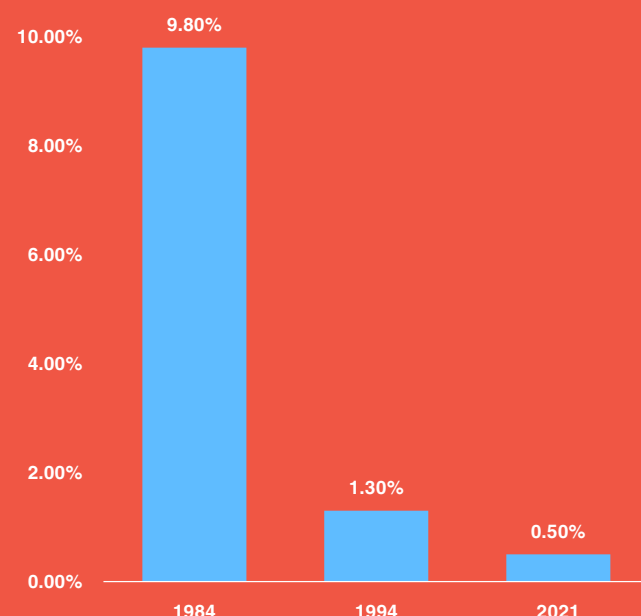
Health systems must provide accurate, accessible information and services to people newly diagnosed with hepatitis B and link them to appropriate peer support.

Civil society organisations and other peer support organisations can provide people with the psychosocial support needed to come to terms with living with hepatitis B. Peer support can be a lifeline for newly diagnosed people seeking connection with others. Peer support offers the opportunity for people to share their experiences and offer support to help overcome the challenges they have faced. But support can be hard to find. Services are only sporadically available globally and are often underfunded.

Lien goes on to describe the reality of disclosing her status:

When I told my husband, then boyfriend, about my status, I was met with empathy and acceptance. Even though he did not know much about the disease and was afraid of contracting it, he chose to love and not stigmatise. Unfortunately, most people do not react with such acceptance. Therefore, I chose not to tell my friends, colleagues, in-laws, or anyone who was not at risk of contracting the disease.

“Worries about my condition crept up again during my pregnancy,” remembers Lien. “Luckily, I had access to a private hospital that specialised in delivery for mothers living with viral hepatitis and my children received hepatitis B vaccinations at birth. Unfortunately, a lot of women in Vietnam do not have the same privilege.”



The emotional and psychological burden of hepatitis B can be especially hard on mothers living with the virus because of the fear and guilt of passing it on to their children.

Mother-to-child transmission (or vertical transmission) is one of the main ways people contract the hepatitis B virus. Even though WHO recommends all pregnant women get tested for hepatitis B, and that all newborn babies receive the vaccine, this is far from common practice.¹⁹ Worldwide, less than half of all newborn babies get immunised against hepatitis B, with the percentage being as low as 4% in some regions.²⁰

Decline in prevalence of hepatitis B in children in Chinese Taipei (Taiwan), the first country to introduce a universal hepatitis B vaccination.²¹

POLICY RECOMMENDATION

Ensure equitable and affordable access to PMTCT for all women.

Around the world, many mothers have to live with the burden of having unknowingly passed on hepatitis B to their children. This failure of the health system creates burden on the woman that may feel shame, guilt and a sense of failure that no one should have to endure. Even though interventions to prevent mother-to-child transmissions are both available and affordable, 43% of births happen without access to prevention services.

While the vaccination of infants with the hepatitis B birth dose is integral in prevention and elimination of mother to child transmission by 2030, the testing and treatment of pregnant women is equally important. WHO

recommendations released in 2020 highlight that testing and treatment of pregnant women is a key pillar to achieving elimination.²¹

Services should be integrated to meet WHO’s goal of the triple elimination of hepatitis B, HIV and Syphilis. Special consideration should also be given to how births that take place outside of medical facilities are able to access PMTCT services and services adapted for this situation. Health systems must ensure that all pregnant women are tested early for hepatitis B, that mothers are provided with treatment if they need it, that all babies are vaccinated at birth, and that women are diagnosed appropriately with the provision of accessible and accurate information.



Danjuma is public health expert and president-elect of the World Hepatitis Alliance and a leading voice for hepatitis patients in Nigeria and across Africa.

“During my clinical practice I was offered prophylaxis to protect myself from HIV but I was not offered hepatitis B vaccination. When I was first diagnosed with hepatitis B, I stopped sharing household utensils, like cups and spoons, with my family which is common practice in African communities. I, like many others, didn’t know it can’t be transmitted through casual contact. I felt a sense of shame and I faced a lot of pressure. The diagnosis really affected my confidence and my mental health.”

I thought that everyone living with hep B would need treatment immediately which is clearly not the case. I thought hepatitis B was a death sentence and I worried about my career and my future.

My behavior at work changed. I acted differently around my co-workers because I was hyper-aware of my condition. I was terrified of transmitting hepatitis B to my patients. I used more personal protective equipment than my colleagues because of my anxiety surrounding my condition.

People diagnosed with hepatitis B are often provided with inadequate information about what their diagnosis means, or how to effectively respond. This can lead to increased stress, and for some, mental health issues, leading to people withdrawing from society and their communities. They fear they are ‘infectious’ or that they will be ostracised. Danjuma’s story is an all too familiar one. Once diagnosed with any communicable disease, people can often isolate themselves. The fear of what they have and how their friends, family and society will react to the news is a

fear that is well founded. Spreading the virus to loved ones is often described by people with hepatitis B as being a main concern. This is exacerbated by a lack of knowledge about how the virus is transmitted, contributing to the misconceptions that hepatitis B is transmitted by hugging, touching etc.²² In a 2020 survey of Chinese and Vietnamese immigrants to the United States, over half of the participants believed that having hepatitis B would have a negative impact on their family.²³

This fear and shame ultimately leads to many people living with hepatitis B to distance themselves from their loved ones. This in turn has a detrimental impact on their mental health. People decide not to get married or have children out of fear of passing on the infection to their loved ones.²⁴ Studies have shown that people living with hepatitis B suffer from higher rates of depression and anxiety, which can lead to self-harm and even suicide.²⁵

It is very common for people diagnosed with hepatitis B to face mental health challenges. People often report feeling ‘alone’ when diagnosed²⁶, with very little support or information available. In many contexts, especially in developing countries, there is added pressure as the medication is not available to them. This is despite treatment costing countries less than US\$23 per year. Being unable to access treatments can create added anxieties and fears for an individual.

It has been a personal journey for Danjuma.



Working in the health sector, I also feared people would know I have hepatitis and that they would discriminate against me. My diagnosis really pushed me to do more, to study more, to understand more and try to find solutions to the problem. It led me on a path of research and education because I wanted to know everything about hepatitis B transmission. I was a victim of a bad health system and it pushed me to find solutions and improve the system. It pushed me to do advocacy.

The major driver of stigma is lack of information. I get emails every day from people who are fired or not considered for jobs because they are living with hepatitis. I also hear from people who get fired upon their diagnosis because their employees believe they will die very quickly because of their hepatitis. With correct knowledge and information and awareness people will stop discrimination.



POLICY RECOMMENDATION

Mental health support must be provided for people living with hepatitis B.

Integrated mental health support, as part of the hepatitis B service provision, is key to ensuring that people living with hepatitis B have the support and connections they need. Civil society organisations have a key role to play in supporting

the mental health and wellbeing of people living with hepatitis B and they should be considered an essential part of support programmes that provide psychosocial support and peer connection to people living with hepatitis B.

CHAPTER

3

STIGMA AND DISCRIMINATION IN HEALTHCARE



Jason found out he was living with hepatitis B in 2011, while living in the Midwest of the United States. This is an area of the country where specialist liver healthcare is limited. His experience of care demonstrates the importance of well-informed medical care providers.



I was living in a rural area of the United States with few specialists. The knowledge of hepatitis B among the medical profession was minimal. I didn't know much about hepatitis B back then, all I knew was that it causes cancer. I was living with hepatitis B and HIV and when the doctors first treated me, it was clear they didn't know much about either. Because my doctors didn't understand my condition they gave me the wrong treatment, which made me very ill.

The relationship you have with a doctor is very important. You and your doctor should be a team and if you can't trust the doctor, you're no longer a team.





People living with hepatitis B have reported facing isolation within healthcare settings. Due to some medical professionals having the belief that hepatitis B is highly transmissible, they can sometimes use extreme caution when working with people living with hepatitis B, such as wearing up to five pairs of gloves to perform simple procedures. In some cases, medical professionals refused to provide care for them at all. The fear of infection has also led to breaches of confidentiality, with nurses disclosing to their colleagues if someone has tested positive for hepatitis B, so they can take additional precautions. This includes sharing the hepatitis status of pregnant women and new mothers, which has led to nurses and midwives refusing to assist in the labour and delivery of hepatitis B positive women and being wary of handling their babies.²⁷



The healthcare professionals just weren't used to seeing people living with hepatitis B and they were not sure how to treat someone living with it. I had to learn to be proactive. Due to the lack of the healthcare professional's education about hepatitis B, I had to leave the area I was living in and move to New York to receive the healthcare that I needed.



Dr. Lok is a world-renowned hepatologist and advocate. Throughout her career she has taken on the cases of people living with hepatitis B, who have been discriminated against when applying to medical school in the United States.



Around 15-18 years ago, I was informed that students were being turned away from studying medicine, dentistry or surgery because they were hepatitis B positive. At the time, the United States Center for Disease Control and Prevention (CDC) recommended that hepatitis B positive medical practitioners notify the hospital and their patients of their status. Following up on one of the cases, I had a conversation with a dentistry school dean who turned away a hepatitis B positive student from the school because he was concerned about the student putting their hands in patients' mouths. The student was not kicked out outright, he was told that a spot was reserved for him and he could return once he has cleared the hepatitis B surface antigen – a marker of hepatitis B infection. However, clearing the surface antigen, is very rare in people living with the virus. This was only the first of many similar conversations I had with medical schools across the country.

In another case, a student from China who contracted hepatitis B via mother-to-child transmission, was told he could not start medical school because of his diagnosis. He was informed just one month before his start date. He had to call his mother, who was so proud of her son for getting into medical school, to tell her that he had been kicked off his course. Now without school or a job and with a yearlong unbreakable lease on an apartment, he reached out to the Hepatitis B Foundation for help. I took on his case, determined to fight against discrimination and advocate for his rights. After a long journey, he was able to graduate from medical school.



Despite the recommendation from the CDC, medical students and healthcare professionals living with hepatitis B still face institutional discrimination. A 2020 analysis of medical schools in one U.S. state found that 43% had policies that required proof of hepatitis B immunity for participation in the education programme.²⁸

The Hepatitis B Foundation, a United States-based non-profit organisation supporting people living with hepatitis B, reports being contacted by students who were refused enrollment to a medical programme or denied the opportunity to begin clinical practice after they tested positive for hepatitis B. As students living with hepatitis B are not always aware of the protections they have under the law, they may fall victim to these outdated, discriminatory policies.²⁹

Dr. Lok continues:

Unfortunately, discrimination does not stop in the education sector. I worked with a surgeon in the Boston area, employed in an academic medical centre, who was found to be hepatitis B positive during an antenatal hepatitis screening. She was willing to start on the antiviral and get back to work. Initially, she was allowed to go back to work because we fought relentlessly for her rights, only to be fired a year later for ‘poor performance’. Before her diagnosis, the surgeon worked at the same institution for seven years with no performance complaints.

There have been no hepatitis B transmissions recorded by a hepatitis B positive healthcare provider in the United States since 1994. But it was only in 2012, that the CDC updated its guidance, reaffirming that a positive hepatitis B status should not disqualify anyone from studying or practising medicine.

A year later, the U.S. Department of Justice launched an investigation on behalf of hepatitis B positive students, which concluded they are protected against discrimination under the Americans with Disabilities Act.



The United States is not the only country struggling with systematic institutional discrimination being faced by people living with hepatitis B. Anti-discrimination policies in many different countries (if in place), are often poorly implemented.³⁰

Misconceptions about how hepatitis B spreads and the transmission risks leads to the avoidance and exclusion of people living with hepatitis B. Even though medical institutions should have up-to-date knowledge of the virus transmission, they often implement outdated guidelines that harm people living with hepatitis B.³¹ Combatting the misconceptions and discriminatory practices is necessary to allow people living with hepatitis B to study and practice medicine.

POLICY RECOMMENDATION

Hepatitis education must be provided to all healthcare professionals, with an ongoing programme of continuous professional development to ensure professionals have up-to-date information.

All healthcare professionals should know and understand hepatitis B, not only specialists. It is only through education that we will achieve a system where someone living with hepatitis B can enter a healthcare system and be met

with compassion instead of fear. Healthcare professionals also need to be vaccinated against hepatitis B and shown that they are not at risk of the disease.

CHAPTER

4 DISCRIMINATION

Stigma and misconceptions about hepatitis B can lead to discrimination against people living with hepatitis B through every aspect of their life, including home, education, healthcare and employment.³² Discrimination policies are evident in migration requirements in many countries, pre-employment health screenings, annual screening and random and ongoing screening can take place as well as in company policies. These screenings can be degrading and serve little purpose within public health interventions, as people who test positive are not linked to care. These policies stop people coming forward for testing and force people living with hepatitis B to hide their condition.

Faisal first found out he was living with hepatitis B in 2014. He studied pharmacology in Bangladesh and as a bright student he was confident that he would find employment once he left university. However, once he entered the workforce, he was met with the cruel realities of discriminatory workplace policies.

I saw a doctor because I had jaundice, and the doctor conducted a hepatitis B test. I tested positive. I was diagnosed with chronic hepatitis B, and I have been on medication ever since.

During my studies, my professors and friends believed that my hepatitis status made me immunocompromised. They told me that I was unfit to work and would die young. After completing my bachelor's degree in pharmacology, I got selected for a job as a medical information officer in a pharmaceutical company. They picked me for a 30-day training session. During the last week of the training session, I was called for a medical test. My test came back positive for hepatitis B.

I was invited to the director's office, and he scolded me for 'spreading the disease' to others. He was convinced that hepatitis B could spread through sharing utensils and would not listen to any data that proved otherwise. He called me 'dangerous to others.' I did not feel like I was living with the virus, I felt like I was the virus.

The company policy was not to hire people living with hepatitis B and my contract was terminated. After receiving the news, I was so disappointed because I showed great results during my 30 days of training. I was not hired based only on my hepatitis B status. I was not compensated for the 30 days of training either, because the company said I wasted their time and resources by not disclosing my hepatitis status. However, I did disclose my status on the second day of my training, but they did not acknowledge it at the time. If the director knew more about how hepatitis B is transmitted and if he knew people living with hepatitis B can still be fit to work, I believe he would change his policies.

Upon my termination, my family was very supportive; they told me a better opportunity is waiting for me. I was quickly disappointed to learn that many pharmaceutical companies around Bangladesh have the same policy. Due to the country's high unemployment rate, sometimes hundreds of people apply for a single open position. People living with hepatitis B are seen as 'ill' and unfit to work and companies avoid hiring them in favour of hiring someone 'fit'.

Although workplace discrimination based on a person's health status is outlawed in many countries, it is still all too common in practice. A systematic literature review of hepatitis B stigma research shows that up to 30% of people living with hepatitis B report workplace discrimination due to their hepatitis status. The stigma is particularly common in the WHO Southeast Asian and the Western Pacific Region.³³

Discriminatory policies may have an effect on the declining mental health in some people living with hepatitis B. Such is the case of a 19-year-old student at Tianjin Normal University, who took her own life in 2015. This followed being ostracised by other students and being forced by the faculty to live alone in a dorm room following a positive hepatitis B diagnosis.³⁴

Faisal continues:

I am now at a loss about what to do with my future. I was considering pursuing a master's degree in pharmaceutical engineering, but it seems futile if I cannot get a job in the pharmaceutical industry because of my hepatitis B status. I briefly considered taking a government job, thinking the government would have anti-discriminatory policies in place. However, I learned that my cousin who took that route got fired because of his hepatitis B status. I never expected this to happen to me. I am still unemployed and I feel hopeless knowing that any company will not hire me based on my hepatitis status.

POLICY RECOMMENDATION

Ensure viral hepatitis testing is confidential, for the benefit of the person being tested, and not required as a condition for employment.

With data showing many people are unaware that they are living with hepatitis B, it is crucial that there is an upscaling of diagnosis and testing. However, testing strategies will have a negative impact if they lead to discrimination. Many organisations have policies that

discriminate against people found to be living with hepatitis B. Both confidentiality when it comes to testing and protection from discriminatory business practices are crucial elements of the public health response to the hepatitis B epidemic.



Dee Lee has been living with hepatitis B since he was two years old. He has first-hand experience of discriminatory workplace policies in China and what he saw and experienced changed his life.

One contaminated medical needle was all it took to contract the virus. As an adult, my mission in the hepatitis sector is to raise the voice of people living with hepatitis B and C who face workplace discrimination.

My home country, China, has a complex issue of viral hepatitis stigma. On the one hand, there is a significant lack of public health education around viral hepatitis, leaving people to believe it can be transmitted through touch or the sharing of utensils. On the other hand, many of my fellow countrymen believe traditional Chinese medicine can help cure the infection. As a big nation, we focus too much on policy and ignore the importance of public health education to help solve these issues. Although policy is very important, it is equally important for the government to engage with people, hear their stories, see the reality of living with hepatitis and the impact of the virus on their lives.

I previously worked for a company where I had to lie about my hepatitis status. I got a friend to take the hepatitis B test in my place. My job there was shocking. I was there to coordinate the active discrimination of people living with hepatitis B. We even had hepatitis B tables in the lunch hall, nobody was allowed to sit with them, and they were not allowed to sit with their other colleagues. I felt terrible. Here I was living with hepatitis B, witnessing the discrimination that was taking place. I had to get out and start fighting this injustice. The rights of people living with hepatitis are basic human rights.

Researchers attribute the hepatitis B stigma in China to confusion about different types of viral hepatitis and misconceptions about how the different viruses are transmitted. Following a major outbreak of hepatitis A in Shanghai in 1988, laws were put in place that permitted employers and universities to screen applicants for viral hepatitis and reject their applications based on their hepatitis status.³⁵ People living with hepatitis B missed out on education and employment opportunities. Children who tested positive were not allowed to enrol in kindergartens and preschools.³⁶

Even though pre-employment screenings for hepatitis B were outlawed in China in 2010, hepatitis B stigma is still widespread due to decades of systematic discrimination. Two 2016 surveys, conducted among Chinese adults with rural backgrounds, revealed that more than half of the respondents were unwilling to hug, shake hands or have dinner with a person living with hepatitis B. A large majority of the respondents (78% and 82%) were reluctant to let their child marry someone living with hepatitis B. One of the major consequences of stigma is the unwillingness to get tested or disclose a positive status for fear of losing employment or marriage opportunities.³⁷ The WHO Global Health Sector Strategy on Viral Hepatitis 2016–2021 calls on governments to “end policies and practices that condone or encourage stigma and discrimination against people at risk for hepatitis or living with hepatitis, especially in healthcare settings and places of employment” as one key step towards achieving hepatitis elimination.

POLICY RECOMMENDATION

Ensure anti-discrimination laws are put in place, enforced and fit for purpose and adequate recourse is given to enable people experiencing discrimination to pursue justice through the legal system.

Anti-discrimination laws that protect people living with hepatitis B against discrimination based on their infection should be put in place, and existing anti-discrimination laws must be properly enforced. Every day people face discrimination and dismissal from work/employment just because they test positive for the virus. Many are on treatment or have an undetectable viral load and do not need

treatment. This is a vaccine preventable disease that is not casually transmitted. This is a violation of an individual's human rights. All institutions must ensure their policies don't discriminate against people living with hepatitis B. People living with hepatitis B also need access to justice if they experience discrimination.



Sidney found out she was living with hepatitis B in 2007, when she pregnant with her son in her home country of Vietnam. A year later, she moved to Australia, to help fill the gap in their workforce in early childhood education. After a decade of living in the country, Sidney applied for permanent residency. It was then that she was met with barriers from the government.

I was living in Australia for over a decade before I applied for permanent residence. I never concealed my hepatitis B status from the authorities and it was not an obstacle for receiving my education and work visa throughout the years. However, applying for permanent residence was different. Shortly after applying, I was given a deportation order based on my hepatitis B status, because the government decided that my treatment would cost the health system too much money. I knew other people living with hepatitis B that got their permanent residence, with the only difference in our cases being that they were not taking medication. Therefore, they were not seen as a burden to the healthcare system. The government saw me not as a person, but as an expense.

I tried everything. I pleaded to the authorities and offered to pay for medication myself. I even considered stopping my medication against my doctor's advice, because I thought it could aid my immigration case. I was told not even the best lawyer could help me avoid deportation. I was desperate.

Low-prevalence countries such as Australia see most hepatitis B cases in the communities most underserved by the health systems; including amongst migrants and refugees. Misconceptions about how hepatitis B spreads, especially associating the virus with poor hygiene, leads to migrant populations being further ostracised.³⁸ Therefore, it comes as no surprise that in a 2016 study on concerns and anxieties among people with



I felt like the government's decision was so unfair, both to my son and me. Australia is the only country my son has ever called home, and he was facing losing it because of me. He can't write or read Vietnamese and he faced being deported to a country where he would be illiterate. Despite all odds, I decided to fight.

This process has taken an immense toll on me mentally, physically and financially. Despite the difficulties I faced, I am very happy I shared my story, because if I left quietly, nobody would know that people living with hepatitis B face discrimination in the immigration process. Even though I was successful, I still read stories of people who have been deported due to their hepatitis status. It is very cruel.

As long as the immigration case officers are approaching real human cases as a set of tick boxes, the process will remain unfair. A 'one size fit all' approach does not work when it comes to real people. There should be more focus on the person behind the piece of paper.



Discriminatory immigration policies exist around the world. For example, the immigration policy of the United Arab Emirates (UAE) states, "In order to be able to obtain a work/residence permit, foreign nationals need to be free of all forms of communicable diseases." Domestic workers, child carers, hospitality workers and beauty and health centre workers must test negative for hepatitis B in order to obtain a work or residence visa. The screening process includes compulsory annual hepatitis B re-testing as a condition for visa renewal.⁴⁰

chronic hepatitis B in Australia, over one-third of participants stated that they do not like to disclose their status to anyone.³⁹ A

POLICY RECOMMENDATION

Ensure immigration policies do not limit the freedoms of people living with hepatitis B because of their hepatitis B status.

Immigration policies must not limit the freedoms of people living with hepatitis B because of their diagnoses. Bans for people living with hepatitis B violate the individual's human rights and discourage people from testing and receiving the care they need.

CHAPTER

5

ADVOCACY

Action must be taken across societies and health systems to address the injustice highlighted in this paper. The policy recommendations outlined, provide governments and decision makers around the world the suggestions on how to tackle stigma and discrimination. But action will only happen with advocacy from individuals, the affected community and civil society.

Many of the people whose stories we have shared in this paper have been motivated by their experience of stigma and discrimination to become activists and advocates for people living with viral hepatitis. They dedicate their

lives to fighting injustice, so others do not have to go through the same experience, tackling discrimination, and prejudices and educating their communities to break down misconceptions.



Arafat decided that what happened to his uncle's wife should not happen to anyone else.



I now spend my last atom of energy in the rural villages, educating the communities about hepatitis B and giving them the information they need to understand hepatitis B and to break the stigma. Fighting stigma and discrimination is the way. We also need to include young people as we raise awareness about hepatitis B.





Jason works with the Hepatitis B Foundation in the USA as a storyteller, sharing his story to inspire others and highlighting to medical professionals and researchers the importance of understanding hepatitis B.



Knowing that I am helping someone else with my story is very important to me. When I tell people that I'm living with hepatitis B it's amazing how many people don't know what that is. People living with hepatitis B also need to hear each other's stories. We need to draw strength from one another. I also speak to scientists and use my story to show the importance of hepatitis B research, and I hope this motivates them to find a cure for this disease. A cure would mean everything to me because I still have the virus no matter how strong I am. Having a cure would mean I'm free.



Danjuma works to advocate for the prevention of mother-to-child transmission of hepatitis B in Nigeria and in Africa:



We need to screen all pregnant women for hepatitis B and link them to care and vaccinate all babies against hepatitis B. There is a huge burden of guilt for women who unknowingly pass down hepatitis B to their children. They feel guilty and ashamed and feel they have failed by passing on a deadly disease to their children, but it is not their fault. The health system has failed them. We can easily and affordably prevent the transmission of hepatitis B and it's horrendous that we have not done this for all babies and mothers.



Lien uses her story to raise awareness about hepatitis B and show people that you can still live a fulfilling life, despite your diagnosis. She is an advocate on the global stage, speaking at international conferences and events and highlighting the need for more research funding to find a cure for hepatitis B.



I lost my opportunity to study abroad because of my status. A friend of mine lost the chance to have a life partner because she was rejected upon disclosing her diagnosis. Other people I know lost their jobs. The elimination of hepatitis for me means opportunity. A hepatitis B cure is something everyone living with hepatitis B longs for; it would also be a cure for the social illness of hepatitis B stigma.





Dee founded an organisation to help others fight employment discrimination in China. He works with organisations to make their workplaces welcoming to people living with hepatitis B.

Advocacy and campaigning are the best ways for the civil society to educate wider society about the realities of living with hepatitis. I founded the Inno Community Development Organisation with this goal in mind. Our mission is to eliminate stigma in the workplace for the over 120 million people in China living with viral hepatitis. We give a voice to workers who experience discrimination based on their hepatitis status, whether they are fired because of it or disqualified during the interview process. We take a hands-on approach to combating stigma, going directly to the business owners to inform them that discrimination goes against the government policy.



Sidney's story of having her visa rejected spread online and led to an online petition being started, which attracted over 32,000 signatures. Because of this advocacy, the government of Australia granted Sidney a visa extension and she and her son could stay in the country.

I had the opportunity to talk to many journalists and politicians. I gathered my community, my doctors and many other medical experts in the hepatitis field in Melbourne, friends, family, colleagues and supporters to write letters to the immigration minister to plead my case. Despite all the effort, I was rejected again so I sold everything, packed my stuff and said goodbye to my friends and relatives, ready to go back to Vietnam.

Less than 48 hours before I was supposed to board my plane, I was granted a one-year visa extension and on 5 January 2021, I was granted a five-year employment visa. All of the advocacy has paid off.

POLICY RECOMMENDATION

Increase funding for hepatitis B programmes and research to reduce stigma and increase equity in society.

Compared with other infectious diseases, hepatitis B has one of the lowest research budgets. This underfunding leads to a lack of innovation in treatment and care models and leaves health systems with only a partial picture of hepatitis B's true impact on communities.

Funding for the hepatitis B response is also lacking. Despite the lower costs for the hepatitis B medication, people still live with hepatitis B, unable to access the treatment they need. With no global funder for the hepatitis response, low- and middle-income countries, which have the highest burden of hepatitis B, are being left alone to tackle the hepatitis B epidemic.

Research funding is also needed to understand and address the stigma and discrimination faced by people living with hepatitis B. Lessons can be learned from the HIV response. The Undetectable = Untransmittable (U = U) initiative, launched by the Prevention Access Campaign, promotes the fact that people living with HIV on effective HIV treatment cannot pass it on to others. This fact has had a positive effect in reducing the stigma reported by people living with HIV.⁴³

Research is ongoing towards a hepatitis B functional cure, but progress is glacial. Funding is needed to accelerate action towards developing a hepatitis B cure, which could help address some of the issues outlined in this paper, but only if the cure is available equitably and affordably to everyone who could benefit from it.⁴¹

CONCLUSION

Despite the low costs of hepatitis B medication and the availability of a vaccine, many people living with hepatitis B are still unable to access the treatment and preventative measures they need. With few global funders supporting the hepatitis response, low-and middle-income countries who face the highest burden of hepatitis B, are being left alone to tackle the epidemic.

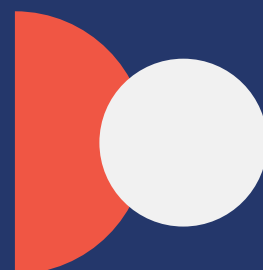
Policy makers must act now to improve the lives of the millions of people who are currently impacted by hepatitis B. We cannot leave people behind.

The lives of people living with hepatitis B are impacted by stigma and discrimination every day. Their human rights must be protected. Policy makers need to work with the civil society and the affected community. With concerted effort we can end stigma and discrimination and improve the lives of millions of people affected by hepatitis B around the world.

HEPATITIS CAN'T WAIT

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WORLD HEPATITIS ALLIANCE

Email

contact@worldhepatitisalliance.org

Address

86 bis route de Frontenex
Case Postale 6364
1211 Geneva 6