



## Mark of resistance

Chronic hepatitis B infection is heavily stigmatized around the world. Now, patients are finding a voice to push back and demand an end to discrimination and isolation. **By Claire Ainsworth**

Looking across the factory canteen, Dee Lee knew things had to change. Set aside from the rest of the room was a table where colleagues infected with hepatitis B were forced to sit. Misconceptions that the virus could be transmitted through casual contact, such as sharing food or utensils, meant that these workers were heavily stigmatized. Segregation was just one penalty. Another was being summarily sacked, a task that fell to Lee as public-relations manager for the factory, one of the largest in China.

But Lee had a secret: he, too, had hepatitis B, contracted from a contaminated needle when he was just a toddler. To pass the medical examination for his job, he had persuaded a friend to stand in for the blood tests. The dishonesty soon became unbearable. “I felt absolutely tormented,” he says. Ultimately, Lee’s conscience won out over the lure of his well-paid career, and he resigned.

Fifteen years on, Lee’s situation remains far

from unusual. And it’s not unique to China. Across the world, the stigma against hepatitis B infection blights millions of lives. People lose educational opportunities, jobs, their families and even their lives. Overwhelmed by anxiety and loneliness, some die by suicide<sup>1</sup>. Others avoid seeking treatment until it is too late. For too many people, living with hepatitis B means dying from shame.

Hepatitis B stigma – a mark that singles people out as different or lesser – is fuelled by a combination of ignorance about the virus and misunderstandings about how it spreads. Affected individuals not only are shunned by society, but also condemn themselves. Even well-educated people fear telling anyone they have it, and this prevents them from accessing care. “It’s completely unnecessary,” says Su Wang, a former president of the World Hepatitis Alliance (WHA) and medical director of viral-hepatitis programmes and the Center for Asian Health at the Cooperman Barnabas

Health Center in Livingston, New Jersey, who herself has hepatitis B. The virus cannot spread through casual contact, such as shaking hands (see ‘Three myths’). There’s an affordable vaccine that cuts transmission – including the main route in many parts of the world, from mother to child – and there are generic antiviral drugs that suppress the virus<sup>2</sup>, which prevents someone from infecting others, she says. Yet stigma is one of the key factors stopping people coming forwards for testing or treatment. A mere 10% of infections are estimated to have been diagnosed<sup>3</sup>.

As well as threatening to scupper the World Health Organization’s goal of eliminating hepatitis B by 2030, the gap in diagnosis could negate the potentially transformative effects of a cure, which many scientists think is in reach. “Even if we discovered a cure tomorrow, we wouldn’t put a dent in the disease and deaths associated with hepatitis B, because the people with hepatitis B are not in care,” says

Thomas Tu, a virologist at the University of Sydney in Australia, who has the virus himself.

Prejudice might be a barrier to developing such a cure in the first place. Difficulty in recruiting patients for research and clinical trials hinders translation of scientific discoveries about the virus into effective, timely treatments, says Philippa Matthews, a clinician and virologist studying the interactions between hepatitis B and host genetics at the Crick Institute in London. The social aspects of the infection and how it affects patients' ability to engage with clinicians are complex, but Matthews thinks that societal attitudes are a significant obstacle: "Stigma just comes out time and time and time again," she says. "And when you talk to people with lived experience of hepatitis B, you realize how far-reaching that is and how people fear being identified."

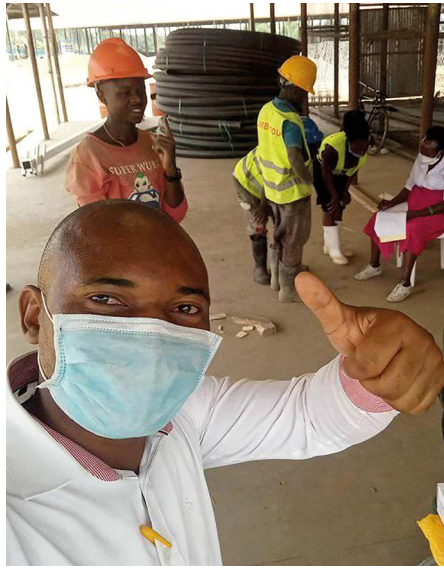
These hurdles have fuelled a growing realization that beating hepatitis B means addressing prevailing mindsets as well as biology. Attempts to counter stigma at multiple levels – political, institutional and personal – are gathering momentum. And important initiatives are connecting individuals with hepatitis B – initially for mutual support, but ultimately to push back against stigma. "I don't think discrimination can be eliminated," says Lee, who, on quitting his job, founded the Inno Community Development Organisation in Guangzhou, China, a workers'-rights charity that supports factory workers in China living with the virus. "But we can still fight it, no matter how difficult it is."

### Ostracism and danger

One issue for people trying to eradicate hepatitis B's stigma is a paucity of research. In 2018, Matthews and her colleagues performed a systematic review of literature examining this problem<sup>4</sup> and found just 32 studies; other diseases, such as HIV, have hundreds. Geographical coverage was also uneven – two studies looked at stigma in Africa, where hepatitis B is highly endemic. Even so, their findings corroborate anecdotal stories about the appalling consequences of stigma, including those in a report issued in November 2021 by the WHO (see [go.nature.com/3mkzjj](https://go.nature.com/3mkzjj)).

Arafat Bwambale, a public-health officer based in Kasese, Uganda, had an uncle who died of hepatitis-B-related liver cancer. Bwambale says his uncle's wife was blamed: she was accused of witchcraft, sexually assaulted and her house was demolished. "She feels like she was very isolated and shouldn't have had to bear the agony and misery that she went through."

Other forms of stigma are less violent but still devastating. Communities routinely refuse to



Outreach worker Arafat Bwambale.

share utensils and food with affected individuals, and ostracize families with affected family members. Hepatitis B infections are often detected during routine antenatal screening, so women are frequently blamed for infections that they probably acquired from their own mothers. Some face intense pressure from their families to abort wanted pregnancies, says Wang.

**"People need to just get mad and see there's so much injustice around this."**

Stigma and discrimination by employers, organizations and governments limit the opportunities of people with hepatitis B. Individuals find themselves barred from certain university courses, or unable to find employment. This includes those in the global north, where universities often fail to update discriminatory admissions policies for medical courses, despite anti-discrimination laws being in place. In the United States, for example, students with hepatitis B are protected by the Americans with Disabilities Act, but some have nonetheless had medical-school acceptances rescinded owing to their infections<sup>5</sup>. In many other parts of the world, health-care professionals with hepatitis B are completely excluded from practising in some contexts, says Freeland. Even those who don't face such bans are too frightened to go public, says Wang, who herself fretted about the consequences of doing so. What's more, people with hepatitis B are barred from deployment in the US military. This puts their careers at

risk, says Catherine Freeland, director of the public-health programme at the Hepatitis B Foundation, a patient-advocacy charity based in Doylestown, Pennsylvania. "That's a significant consequence that's unnecessary, and it's not based on current updated medical guidelines," Freeland adds.

Governments often use hepatitis B infection as an unfounded reason to refuse work visas, even for long-term residents. Some Gulf countries, such as the United Arab Emirates, refuse visas for hepatitis-B-positive applicants seeking domestic work or employment in the food industry, and will expel workers who test positive during their stay, says Freeland. This creates problems for workers from sub-Saharan Africa and the Philippines, who often seek such work there. Racism, sexism and discrimination against marginalized communities can further compound the problem. "It's just this continuous cycle that's really tragic and unnecessary, and it has to do with a lot of misinformation," says Freeland.

All of this exacerbates the tendency for people with hepatitis B to stigmatize themselves. They worry about whether they will be able to marry, or have children. Searching for information online, they come across frightening statistics about the virus's links with infectivity, liver cancer and death. "You've got all of this stuff saying that you are a biohazard," says Tu, who has gone public about having the virus himself. Patients fret about how to limit this risk. Unvaccinated children and infants are very susceptible to infection, so patients pull away even from close family members. This isolation means there is no one to talk to, says Tu. "So even though there's 300 million people around the world with hepatitis B, in the end, you feel quite isolated and alone."

A lack of awareness and information about hepatitis B are major factors driving stigma – even among people who have been diagnosed. "Some of them are not very well versed in terms of what's happening within them," says Tongai Maponga, a clinical researcher studying viral hepatitis and liver cancer at Stellenbosch University in Cape Town, South Africa, and one of Matthews's collaborators. Part of the problem is that some clinicians fail to effectively communicate with patients, he says.

Another factor is ignorance about how hepatitis B spreads. In the early 1980s, confusion of the infection with hepatitis A, a virus spread by the oral-faecal route, led authorities in China to ban anyone with viral hepatitis from working in the food industry or civil service. The bans have since been repealed, and anti-discrimination laws and regulations enacted, but the prejudice lingers<sup>6</sup>. Confusion with other stigmatized viral infections, such

as HIV, which people often associate with promiscuity, can also worsen the problem, says Maponga. Health-care workers can be surprisingly ignorant about transmission: they sometimes refuse to touch patients, says Wang. Meanwhile, policymakers are failing to modernize outdated guidelines. “The knowledge gap is just crazy on all levels,” says Freeland.

Cultural beliefs and superstition play a key part in many countries. “Most of the people here [Uganda] in the traditional society think that viral hepatitis is caused by rudimentary African witchcraft, a lizard moving on your body, and other myths,” says Bwambale. Similar beliefs are common in other sub-Saharan countries, such as South Africa, says Maponga. Patients will spend months visiting traditional healers before seeking medical care. Similarly, according to Lee, traditional beliefs in China hold that hepatitis B is a form of bad energy that can spread through simple contact. As a result, people can waste time on fruitless folk remedies.

### The information imperative

Given that stigma is influenced by cultural factors, interventions to combat misconceptions need to be tailored to local circumstances for maximum effect. Western Uganda, for example, has suffered decades of conflict and is ethnically and linguistically diverse. Bwambale and his colleagues base their hepatitis B outreach efforts there around the Great Lakes Peace Center, a charity promoting dialogue and peace among young people in Kasese. The centre disseminates health messages translated into local languages and holds barazas – traditional meetings at which communities can talk about the challenges they are facing, says Bwambale.

Radio is a very important means by which people in Uganda, especially in remote locations, receive health information (see [go.nature.com/3c8uy](https://go.nature.com/3c8uy)). So Bwambale and his team have designed radio jingles to educate listeners about hepatitis. The efforts are working, especially for people living with the condition, says Bwambale. “Psychologically, spiritually, they feel like they are in a better position.”

In Cape Town, Maponga’s team talks to people with the virus one-on-one, away from a hospital setting. Maponga finds that educating patients about hepatitis B in this way also helps to counter stigma, because many people then bring their family members in for counselling and testing. That goes a long way, says Maponga, “because then their own families are made aware, they’re educated about the condition, and so they’re able to give the proper support”.

## Three myths

**The leading causes of hepatitis B stigma are a lack of awareness of the virus and misconceptions about how it is transmitted.**

**MYTH:** Hepatitis B spreads through casual contact, such as sharing food or utensils.

**FACT:** A key route of transmission, accounting for most cases in some parts of the world, is from mother to child. This can be prevented by vaccination within 12 hours of birth. Hepatitis B is also spread through sexual contact or through blood, including objects that might have traces of blood, such as needles used for injections, razors and tattoos. Shaking hands or sharing food and utensils is safe.

**MYTH:** Poor hygiene or bad sanitation causes hepatitis B.

**FACT:** Some other kinds of viral hepatitis, such as hepatitis A, spread through contaminated food or water. Hepatitis B does not.

**MYTH:** Hepatitis B is an automatic death sentence.

**FACT:** Hepatitis B is currently incurable but can be very effectively treated with antiviral drugs that not only keep the virus in check, but also prevent transmission. People with the disease can have a normal life expectancy: “You can live a very happy, fulfilling life with hepatitis B,” says Wang. “It is definitely not a death sentence. Once you have that diagnosis, you can actually do something about it.”

Maponga’s team is collecting the patients’ stories to better understand the challenges they face and to inform clinical research.

Patient-advocacy groups are also tapping into the power of storytelling to dismantle prejudices. In 2017, the Hepatitis B Foundation started a project called #justB, in which people with hepatitis B told their stories on video (see [go.nature.com/3mnmkd](https://go.nature.com/3mnmkd)). Participants came to a series of training sessions, where they met others with the virus – an emotional experience for all involved. “It’s often the first time that they’ve ever talked about it in a group,” says Freeland. “For a lot of people, they haven’t even shared it with family members or close contacts.” The project has now been expanded into an online story bank, which the foundation is using to spread awareness and normalize

conversation about the virus, says Freeland.

Meanwhile, Matthews and her colleagues are establishing a UK initiative called HBVoice, which aims to bring academics, clinicians, community organizations and non-governmental organizations together with people with hepatitis B in a bid to address stigma and improve the representation of patients in research and the development of clinical programmes (see [go.nature.com/3fydq](https://go.nature.com/3fydq)). “You need people who have actually have this personal experience to champion it, but those people need a platform and a network and a support structure and a way of directing their energies and experiences in a way to make it heard,” she says.

Recalling his sense of isolation at diagnosis, Tu set up an online community, HepBCommunity.org, to help others in the same position. “For me, a chat forum was the perfect way to do that because you didn’t need to identify yourself,” he says. As well as connecting affected individuals, the forum links them to accurate information, supplied by clinical experts who, like Tu, are unpaid volunteers.

Although its initial role is as a support network, Tu hopes the online community will help to foster the formation of a cohesive group to advocate for people with the virus – not only to challenge stigma and discrimination, but also to demand more resources for research and treatment. With this in mind, he plans to train participants to effectively communicate with policymakers, pharmaceutical companies, clinical-guideline panels and researchers. The community currently has 600 members, and Tu hopes to secure funding to expand it further. He concedes, however, that money isn’t the only hurdle. “There’s not that many people who are willing to stand up and say they have hepatitis B because of that stigma,” he says. “And that’s really limiting what we can do.”

Things are changing, albeit slowly. The more people go public, the more it encourages others to do the same – and the louder the voice of the hepatitis B community will become. “People need to just get mad and see there’s so much injustice around this,” says Wang. “I think it’s the shame that keeps people from saying, ‘Hey, this is not right. I demand more,’” she says. “We all deserve access to care.”

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1. Kan, Q., Wen, J. & Xue, R. *Lancet* **386**, 245–246 (2015).
2. Gerlich, W. H. *Intervirology* **57**, 202–211 (2014).
3. The Polaris Observatory Collaborators. *Lancet Gastroenterol. Hepatol.* **3**, 383–403 (2018).
4. Mokaya, J. et al. *Wellcome Open Res.* **3**, 29 (2018).
5. Moraras, K., Block, J., Shiroma, N., Cannizzo, A. & Cohen, C. *Public Health Rep.* **135**, 13S–18S (2020).
6. Wallace, J. et al. *Int. J. Equity Health* **16**, 137 (2017).