HBVoice – A Call for Advocacy to Eliminate Hepatitis B Virus Infection

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Abstract

Hepatitis B virus (HBV) infection poses a threat to public health, yet receives little attention and investment. This neglect is reflected in poor advocacy and poor health outcomes. Increased HBV awareness among patients, the public, healthcare providers, funders, the private sector, academia and policy-makers is essential to support progress towards the WHO goal to eliminate viral hepatitis as a public health threat by 2030. Provision of high quality patient-centric care informed by an active and ambitious research agenda requires equitable representation of affected individuals and communities. This article explores challenges affecting HBV patients and their families, identifying barriers that have inhibited their engagement. Drawing on precedents set by movements representing communities affected by other chronic infections, we highlight multiple opportunities to advance the HBV agenda, with an urgent need to harness and amplify the patient voice.

Comment

Hepatitis B virus (HBV) infection is estimated to affect around 300 million individuals worldwide, but has been neglected by healthcare provision, education, research and policy.[1,2] In light of the World Health Organisation (WHO) goal to eliminate viral hepatitis as a public health threat by the year 2030, there is an urgent need for enhanced advocacy for HBV. Organisations representing and led by individuals with TB, HIV and HCV infection have set a precedent for the provision of infrastructure, education, peer support, fund-raising, and advocacy, often with support from large international donors. Parallel examples of advocacy for HBV have been more limited to date, highlighted by a patient describing the HBV Community as 'the forgotten people' (Appendix p1). Enhanced inter-disciplinary action is urgently needed to promote and diversify representation of people with lived experience of HBV infection, which can have far-reaching benefits (Figure 1). We convened an interdisciplinary group to gather evidence and set out a framework for action, considering the challenges and barriers to engagement, and reflecting on the need for patient voices to drive progress.

Many communities most affected by HBV infection have been systematically under-served by existing healthcare infrastructure. Neglect is faced by many countries where chronic hepatitis B (CHB) infection is highly prevalent in the general population. In high-income nations, CHB primarily impacts ethnic minority groups, who are often sidelined by clinical services, and may feel disengaged, marginalised and lost in the system. Migrant populations face further challenges of discrimination, high mobility, unfamiliar healthcare systems, and lack of trusted healthcare providers.[3] CHB is also more prevalent in other groups at risk of marginalisation and discrimination, including subgroups of the LGBTQ+ community, those experiencing homelessness and substance use disorders, and prison populations,[4] for whom HBV screening, vaccination, and links to stable long-term clinical care are not systematically provided. Hepatitis Delta co-infection affects a minority subgroup of those with CHB who are even less well represented by appropriate representative services, data, advocacy and resources.[5] Developing flexible services, rooted in an understanding of the needs and experiences of different communities will enhance access to - and uptake of - screening, surveillance and treatment.

Globally, the majority of those with CHB are currently not treated,[6] and therefore may not be motivated to engage with clinical services. In the minority who are eligible for therapy, daily tablets may be

burdensome, with concerns about side-effects or toxicity. However, with increasing investment in HBV drug discovery, improved engagement of affected individuals, both on and off treatment, is essential to support the success of clinical studies and promote equitable access to new medicines and vaccines. If curative therapies emerge, strong connections between patient groups, industry and clinical services, coupled with translational research, will be crucial to ensure high uptake.

Promoting quality of life for individuals with CHB can only be done through an advanced understanding of the diverse impacts of infection, which are often overlooked.[7] Even in the absence of significant liver function impairment, chronic symptoms include fatigue, nausea and pain, and psychiatric morbidity is common.[8] Due to stigma, some have described avoiding social interactions or personal relationships, resulting in loneliness and social isolation.[8] Discrimination can lead to refusal of insurance, mortgages or visa approvals, and has impact on financial security, education, housing, childcare, healthcare, travel and careers.[7] Financial considerations may inhibit individuals from engaging with HBV clinical care, including significant out-of-pocket expenses for transport, childcare and time off work to attend appointments, and/or the cost of medication.[8] The work of organisations such as the Medicines Patent Pool is trying to address these cost discrepancies, although the HBV field is currently lagging behind HIV, for example. Recognising and addressing diverse physical, psychological, social and economic consequences of infection requires engagement with the patient community, in order to tackle stigma, and provide interventions that adequately address their needs, such as legislation against discrimination.

In clinical settings, healthcare workers often have limited time, and poor knowledge can lead to provision of inaccurate or inadequate information. Patients may be embarrassed or anxious about asking questions, inhibited by language barriers, or want to find information but lack a trusted and confidential source.[8] Promoting better awareness among patients, healthcare workers and the public will enhance opportunities for education and transparent dialogue, and reduce stigma. Education must account for the needs of different ages and cultures, recognising and representing diverse experiences, non-Western approaches to health, religious beliefs, cultural norms, and lack of recognition of HBV as a valid health concern. Failure to provide written and verbal information in an accessible language is a barrier to equitable engagement with services, and reliance on family members as interpreters can cause anxiety about disclosure. Medical jargon frequently impedes communication, while widely used terminology carries negative connotations (e.g. infection as a ‘burden’, the stigma of being described as ‘a carrier’, ‘infectious’ or ‘contagious’, and the concepts of ‘vectors’ and ‘reservoirs’). Descriptions of engagement

with healthcare services can also be pejorative, such as 'non-compliance' and 'lost to follow-up', risking a culture that judges or blames the patient for gaps in continuity of care, rather than recognising and tackling failures in service provision.

Personal story-telling has emerged as a way to build networks of stakeholders, tackle stigma, overcome isolation, and champion priority issues. Examples of personal testimony from adults living with HBV are presented (Appendix p. 1-3). Peer support and personal testimonies have been used to destigmatise HIV and HCV infection, and can be pivotal in addressing psychological co-morbidity, countering isolation, and improving treatment adherence. Although it can be difficult to encourage patient champions to publicly self-identify, and the success of the peer model in HCV is challenging to emulate for HBV which has no cure, champions in the form of 'patient navigators' (a healthcare professional, community representative, or a peer with HBV infection), have been proposed to support engagement with clinical care.[9]

Patient engagement with HBV research has not been equitable to date. The consent process can feel inaccessible, irrelevant and overwhelming, particularly for those who do not speak a primary local language, and prejudices against involvement of participants from diverse communities. These failings by the research community generate results that incompletely represent the real-world population, and promote distrust among patients and the public. Patient input, including co-design, can be harnessed to help inform culturally relevant and accessible clinical studies, built on evidence of the priorities and needs of people living with CHB.[10] Highlighting an awareness of the need to bring patients into dialogue and partnership with clinical research, the Hepatitis B Foundation in partnership with the FDA convened the first externally led Patient-Focused Drug Development Meeting on HBV in 2020. Future such engagement events will enhance involvement of the HBV community in planning priorities for research, as well as providing education and raising the profile of the infection.

We have set out the need for enhanced representation of the HBV community to support advances in diagnosis, surveillance, therapy and prevention, to drive patient-centric research and optimise equitable access to new therapies as they emerge (Figure 1, and supporting evidence Appendix p. 4-7). Advances will require considerable effort, resources, and multi-sectoral partnership, but are crucial to support progress towards HBV elimination targets.

Figure 1 Legend: Summary of inter-related domains that can be enhanced through improved advocacy for under-served individuals and communities affected by hepatitis B virus (HBV) infection. This image was created to summarise themes arising from discussion with a working party of healthcare workers, community support groups and people with lived experience of HBV, together with evidence drawn from the literature (Appendix p. 9-13). Figure created in BioRender.com with license to publish.

Contributors' statement

Conceptualisation - PCM, AME

Project administration - PCM

Supervision - PCM, AME

Writing – original draft - PCM, JVL, AME

Writing – review & editing - all authors contributed

Declaration of interests

CC declares that the Hepatitis B Foundation receives independent grants for public health programming, outreach and education (including Gilead Sciences, VBI Vaccines, Dynavax Technologies, Arbutus Biopharma, Janssen, GSK, BMS, Antios) and serves on advisory committees for Gilead Sciences and GSK; she has also received GSK support for attending meetings including AASLD 2019. JVL has received grants and speaker fees from AbbVie, Gilead Sciences and MSD and speaker consultancy fees from AbbVie, Gilead Sciences, Intercept, Janssen, MSD, Novo Nordisk and GSK, outside the submitted work. AME has received personal consultancy fees and payments for lectures, presentations and educational events from Gilead Sciences and GSK. PCM is funded by the Wellcome Trust, and receives a contribution to funding a PhD studentship from GSK. JC serves on a patient advisory committee for GSK. SW is a voluntary board member for World Hepatitis Alliance and the Hepatitis B Foundation, has received payments/honoraria from CME Outfitters, FocusMed education, and declares funding contributions to her research institution and to the World Hepatitis Alliance from Gilead Sciences.

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