

Delivering for Equity: the marginal role of people with hepatitis B in policy development

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BACKGROUND

The *Global Health Sector Strategy for Viral Hepatitis 2016-2021* calls for the development of national plans to direct the implementation of interventions to eliminate viral hepatitis. The existence of policy itself recognises that hepatitis B is a health condition of consequence and which requires an informed and coordinated response.

In 2013, the World Hepatitis Alliance supported by the World Health Organization (WHO) conducted its second survey of WHO member states' activity on viral hepatitis. Of 126 members responding, over one-third (37.3%) reported having a national strategy or plan. There are significant limitations given the self-reported nature of the findings, and the lack of interrogation of the quality, scope and implementation of the available plans. The report described some of these strategies as being "more a series of uncoordinated programmes than a cohesive strategic approach" (World Hepatitis Alliance, 2010, p. 3).

This provides the context in which the role of people with hepatitis B in national responses are marginalised and raises issues of equity for people with hepatitis B within national responses.

Strategic Aims

Policies from Taiwan and Australia specifically seek to reduce deaths resulting from hepatitis B infection, while the World Health Organization and Vietnam plans seek to increase access to health services by people with or at risk of hepatitis B, while the Indonesia Ministerial decree does not clearly articulate an aim.

Australia is the only jurisdiction that includes an additional top-level aim of reducing the social impact of the infection, although Indonesia does seek to reduce the socio-economic impact of viral hepatitis. All plans identify the need to increase the numbers of people being diagnosed and accessing clinical management services; improve the data informing national responses to hepatitis B, albeit primarily that of improving surveillance data, and raising public awareness.

Discrimination is noted as an issue in the Australian, Indonesian and the World Health Organization policies, although none respond to the need for an investigation of the drivers of discrimination.

CONCLUSIONS

While seeking to develop "comprehensive and cohesive" policies and a "radical change" to the response to viral hepatitis as sought by the World Health Organization (p. 7), current policy responses to hepatitis B at a global and national level invariably position improving clinical access as central to addressing the impact of the infection. The policy ignores the social, cultural and legal drivers that affect the lives of people with hepatitis B including those directly affecting access to clinical services.

Hepatitis B policy responses focus on the absence of disease, and given the lack of a cure for the infection, the absence of infirmity. The social consequences of the infection are effectively ignored within policy. The World Health Organization definition of health is not used in policy discussions or documents, nor are any of the other global health promotion frameworks.

Health policy needs to contextualise and address issues that relate to the lived experience of hepatitis B including the drivers for identifying gaps in how people respond to the infection. While recognising hepatitis B as a biomedical condition, reducing its burden requires interventions that lie beyond the clinic.

METHODS

A content review of the constituent elements of global, regional, and national strategies from five countries (Taiwan, Australia, Germany, Indonesia and Vietnam) was conducted to examine the role of people with hepatitis B within the development of the strategies, and of their proposed roles in their implementation.

Public Health responses

While each of the plans acknowledges that hepatitis B is a public health burden, only the World Health Organization and Australian strategies specifically state the need for a public health response, with the global strategy being the only strategy defining what is meant by this. Other plans seek to improve access to specialist clinical services, with little discussion of the role of the broader health sector.

Quality of life is only mentioned in the Australian policy, where the issue is described as the ultimate goal of hepatitis B clinical management. Rather than seeing a person with hepatitis B as one part of a community, the response to this issue in the strategy focuses on health sector professional development. This neglects a lived experience of hepatitis B that occurs within families as an intergenerational chronic infection and where communities are integral in supporting quality of life.

REFERENCES

Available from the author.

CONFLICTS OF INTEREST

No conflicts of interest.

RESULTS

People with hepatitis B play a marginal role global and national viral hepatitis strategies. The *Global Health Sector Strategy on Viral Hepatitis 2016 – 2021* focuses on activity to be conducted within the health sector. This ignores HIV policy development lessons where the virus – its transmission and clinical management are recognised as being essentially affected by issues outside the health sector. While a desire to align the HIV and viral hepatitis strategies is noted, this alignment is selective.

There is a clear diminution of the expectations of the role of people with hepatitis B within global policy in comparison to that of people with HIV. While the *WHO Global HIV strategy* notes people with HIV being involved in all aspects of a national response, the role for people with viral hepatitis is reduced to ensuring that "strategies and programmes ... result in better targeted and acceptable services" (p. 39). People with hepatitis B are only expected to identify the acceptability of health services, rather than a systemic and profound involvement in policy development or programme coordination and delivery.

Other issues not addressed include a comprehensive whole of government response, legislative review of discrimination, marginalisation, educational access, immigration implications, cross border people movements, migrant workers.

Living with hepatitis B

Some of the specific issues related to living with hepatitis B that are not acknowledged within policy include:

- Living with an infection, which is not necessarily a primary focus in a person's life given its asymptomatic nature and the systematic lack of provision of information to people with hepatitis B across their experience of the infection.
- An infection that is transmitted, and in a social sense carried, within extended families across generations, often with devastating effects including multiple deaths because of the infection.
- A complex clinical description of the infection within biomedicine, intersecting with a population most affected by hepatitis B coming from non-English speaking and culturally diverse backgrounds.
- Where disclosure of the infection has the potential for significant implications for education and employment access, and in complicating personal and social relationships.

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