

“They feel shame sometime, but that is why we need to talk to them...we need to tell them how important it is not to feel shame”: Addressing stigma and shame to improve hepatitis B care in Aboriginal & Torres Strait Islander communities in the Top End of the Northern Territory.

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Background: The Aboriginal health workforce has unique insights given their healthcare experience and interactions with their communities. The aims of this project were to explore their perceptions of hepatitis B stigma and ways to improve care in Aboriginal and Torres Strait Islander communities of Northern Territory’s Top End, Australia.

Methods: We conducted a qualitative study with guidance from the Menzies School of Health Research Infectious Diseases Indigenous Reference Group. The Aboriginal health workforce were asked to participate in semi-structured interviews exploring stigma and shame and ways to improve hepatitis B care. Qualitative data were analysed using inductive and deductive approaches until thematic saturation.

Results: There were fifteen semi-structured interviews with participants representing eight different communities. The experience of shame was reported to be common for individuals diagnosed with hepatitis B and has many impacts including feelings of fear related to transmitting the virus, to being isolated, and to being at fault. Factors contributing to stigma included confidentiality concerns, hepatitis B health literacy, intersecting healthcare-related stigmas, clinic structures, communication barriers and poor engagement of Aboriginal health workforce skills. Improvements in care can be achieved through improved communication and education, increased field-based health services, improved Aboriginal health workforce engagement and an increased emphasis on community connection.

Conclusions: Hepatitis B related shame is an important issue and impactful in Aboriginal and Torres Strait Islander communities in the Top End of the Northern Territory. There are many facets to shame in these communities, as well as structural factors which contribute to stigma. However, when you work in partnership with the Aboriginal health workforce and communities, there are pathways to improve care and diminish the impact of shame.

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