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# “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”: Hepatitis B related shame and improving hepatitis B care in Aboriginal and Torres Strait Islander communities in the Top End of the Northern Territory, according to the Aboriginal health workforce

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## Abstract

**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 related shame and ways to improve hepatitis B 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 was asked to participate in semi-structured interviews exploring hepatitis B related shame and ways to improve hepatitis B care. Qualitative data were evaluated using reflexive thematic analysis.

**Results** There were fifteen semi-structured interviews with participants representing eight different communities. The experience of shame was reported by the Aboriginal health workforce to be common for individuals diagnosed with hepatitis B and comprised feelings of fear related to transmitting the virus, to being isolated, and to being at fault. Shame was mediated by poor health literacy, communication, the lack of culturally safe spaces and was perpetuated by intersecting stereotypes. Improvements in care can be achieved by utilising the Aboriginal health

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workforce more effectively, improving communication and the availability of culturally safe spaces, emphasising community connection, and reframing hepatitis B as a chronic condition.

**Conclusions** Hepatitis B related shame was an important issue and impactful in Aboriginal and Torres Strait Islander communities in the Top End of the Northern Territory. There were many facets to shame in these communities and it was mediated by several factors. The Aboriginal health workforce has emphasised several pathways to improve care and diminish the impact of shame, such as improving communication and the availability of culturally safe spaces.

**Keywords** Stigma, Hepatitis B, Aboriginal and Torres Strait Islander health

#### Text box 1. Contributions to the literature

- There is limited exploration of hepatitis B related stigma and shame in Aboriginal and Torres Strait Islander communities.
- Hepatitis B related shame was common and impactful in Aboriginal and Torres Strait Islander communities in the Top End of the Northern Territory, according to the Aboriginal health workforce.
- Pathways to reduce hepatitis B related shame in these communities, according to the Aboriginal health workforce, included improving communication, utilising the Aboriginal health workforce more effectively and creating more culturally safe spaces.

## Background

Hepatitis B related stigma creates barriers to accessing healthcare and perpetuates poor health outcomes [1–3]. Aboriginal and Torres Strait Islander people are disproportionately affected by hepatitis B in the Northern Territory, with prevalence estimated up to 6.1% [4, 5]. Hepatitis B can lead to cirrhosis and hepatocellular carcinoma, with poor outcomes noted in this population [6]. Aboriginal and Torres Strait Islander people are a priority group according to Australia's national hepatitis B strategy, and reducing hepatitis B stigma is a goal of this same strategy [7]. Hepatitis B related stigma is common in many populations, but there has been limited exploration of hepatitis B shame or stigma in Aboriginal and Torres Strait Islander communities, with only one study in this region describing a fatalistic view of the condition [1, 3, 8–13].

Stigma is characterised by the co-occurrence of labelling, stereotyping, alienation, discrimination and a loss of status in a situation where power is exercised [14]. Shame is not considered synonymous with stigma, but reflects a cultural identity disruption with a loss of connection with community and family [15]. Morgan and colleagues illustrated the importance of shame in Aboriginal communities [16]:

*It is a powerful emotion resulting from the loss of the extended self, and it profoundly affects Aboriginal health and health care outcomes (p. 598).*

It has therefore been suggested that stigma related research involving Aboriginal and Torres Strait Islander people requires a broader scope, which incorporates the notion of shame [15].

The impact of hepatitis B stigma has been shown to contribute to delays in diagnosis and accessing healthcare in different communities, including in Aboriginal and Torres Strait Islander people [1, 10, 17]. Exploring this in Aboriginal and Torres Strait Islander communities in the Top End of the Northern Territory would assist in defining hepatitis B stigma and shame and may also suggest pathways to reduce its impact on healthcare access.

The Aboriginal health workforce has unique insights given their interaction with individuals throughout their communities. These roles have been defined as involving health promotion, clinical service and cultural brokerage [18]. We defined the Aboriginal health workforce to include both individuals from local communities who are employed in healthcare but also community workers within third sector agencies, such as research institutes, who work in health care promotion and community-based health research. This workforce has insights into both the care that is provided, and the experience that individuals go through when diagnosed with hepatitis B. They are well placed to inform how communities and individuals are affected by barriers to care, including shame, and how hepatitis B related care may be improved in Aboriginal and Torres Strait Islander communities in the Top End of the Northern Territory.

The aims of this project were to explore the perceptions of hepatitis B related shame among the Aboriginal health workforce in communities of the Northern Territory's Top End and to determine possible opportunities to improve hepatitis B care in this context.

## Methods

### Study team

Our team includes Aboriginal members (SMB, PN, GG), who have diverse and extensive experiences in Aboriginal and Torres Strait Islander health, research, and community leadership. They represent different language and cultural groups and have roles as a senior Aboriginal Health Practitioner, Aboriginal Community Workers, and Community Researchers. The non-Indigenous

members of the team (RPS, PB, KH, EVC, MM, AG, JSD, JD) include nurses, doctors, PhD candidates, senior researchers, and hepatitis B program managers. Our team ascribes to the principles of pragmatism and participatory health research, and this project was nested within the long-term collaborations and relationships built over many years during clinical viral hepatitis and Hep B PAST program delivery [19–21]. Emphasis has been on building relationships and practices, which invite reflexivity, adhere to cultural safety principles, establish shared knowledge, and analyse collaboratively [22–24].

### Design

This project was inclusive by calling for volunteers from a variety of communities to provide holistic representation. This was performed by inviting participants from the Aboriginal health workforce attending a hepatitis B course, which was open to all communities, and at outreach hepatitis B clinics, which operates in 18 different communities [25]. While every community is unique, establishing common themes was intended to produce reciprocal benefits to all communities in an equitable fashion by sharing findings that are not currently available, but necessary to improve hepatitis B services in this region. Part of this process is feeding back findings of the study to the Menzies School of Health Research Infectious Diseases Indigenous Reference Group and to Northern Territory health policy makers.

Aboriginal researchers and the Menzies School of Health Research Infectious Diseases Indigenous Reference Group were involved in developing and feeding back on this project methodology, co-designing the process to interview the Aboriginal health workforce rather than people living with hepatitis B, and developing the questions for the semi-structured interviews. The Aboriginal health workforce have an in depth understanding of these issues, and have developed expertise in this area through their experience, a key principle of participatory research [22]. As an exploratory study, both Aboriginal and non-Indigenous members of the research team envisaged that interviewing these experts would be the best first step to gain an understanding of a sensitive issue and how it may impact healthcare delivery.

### Settings and participants

Members of the Aboriginal health workforce attending the hepatitis B training courses were asked to participate in semi-structured interviews [25, 26]. There were two hepatitis B courses based in Darwin, Northern Territory, including one in May 2022 and one in October 2023. Interviews with those consenting were done in person, or via teleconference. We also approached the Aboriginal health workforce working in hepatitis B to participate during clinical outreach visits. Those individuals were

initially approached in person and if interested were then emailed to confirm consent to participate. These interviews were completed via teleconference. These individuals were already known to the clinical services delivering hepatitis B care. Participation was completely voluntary.

### Data collection procedure

After a detailed informed consent discussion, each consenting participant was interviewed in a semi structured way by two investigators (RPS, KH). The questions were designed to examine the attitudes to hepatitis B in general, so not to assume that stigma and shame were or were not present (see Table 1). The gender of the interviewer and interviewee was offered to match. Interviews were recorded and an accredited interpreter was offered, when required, in a language preferred by the participant.

We included participants from a variety of communities in Northern Territory's Top End but no reference to the community's name were made by the interviewers during the interview and if they were inadvertently mentioned, any identifiable information was removed from the transcript. All interviews were transcribed in a de-identified fashion using a professional transcribing service and the original recording stored on the password protected Menzies School of Health Research server. Written consents were stored in a locked cupboard at the Menzies School of Health Research and were only accessible by the Menzies hepatitis B team.

The Human Research Ethics Committee of Northern Territory Health and Menzies School of Health Research approved this study (HREC 2021–4037). The ownership of Aboriginal knowledge and cultural heritage is retained by the interviewees.

### Data analysis

Qualitative data were processed using a reflexive thematic analysis approach to generate themes [27]. As an exploratory study, this was intended to be a first research cycle on hepatitis B shame with a view to implement pathways to improve hepatitis B care, as guided by the interviewed experts. One investigator (RPS) familiarised themselves with the data in the interview transcripts, coded each interview through an inductive approach fitting with the exploratory nature of the study, and then grouped the codes into broader initial themes. Aboriginal (GG, SMB, PN) and non-Indigenous team members (RPS, PB), then worked in partnership to collectively revise and define the themes and ensured the themes were consistent with the stated aims of the research and represented a culturally safe exploration of the data.

**Table 1** Interview guide for semi-structured interview*Introductions*

Reiterate confidentiality/not a test just exploring ideas/ no consequences for care/feel free to speak openly and honestly etc/try not to mention community name

*Background, area of expertise*

Can you tell me about your current role? Specifically touch on:

- your experience with regards to viral hepatitis
- your experience with regards to Aboriginal health

*Hepatitis B care*

How is hepatitis B care delivered in your community?

Do people feel comfortable in coming forward for diagnosis? Why or why not?

Once diagnosed, what would the community and the person feel about the care?

What ways would you improve the way care is delivered in your community?

Is there any way we could change the care provided to help a person come forward for a blood test to diagnose hepatitis B?

Are there any barriers you see which prevent people coming for a blood test? What would they be?

*Hepatitis B knowledge and access to care*

Do you think a person's knowledge about Hepatitis B changes how they access care? How?

Would one tell their diagnosis to their family and friends? Why or why not?

Are there feelings of shame when diagnosed with hepatitis B? (If yes, why? ) Would that be a common feeling in your community? Would knowing more about hepatitis B reduce these feelings? Why or why not?

How can care provided reduce the impact of these feelings?

*Conclusions*

Anything else you would like to discuss about Hepatitis B?

## Results

A total of twenty-four participants were invited to participate during the two hepatitis B courses, and eleven participated in interviews. An additional four participants were interviewed following clinical outreach visits. Therefore, fifteen semi-structured interviews were conducted, and comprised twelve female and three male participants, and eight different communities. There were eleven Aboriginal Health Practitioners, and four individuals involved in health promotion, administration and community-based health research. Interviews took place from May 2022 to October 2023, a prolonged period due to the availability of the investigators and the timing of the hepatitis B training courses. One interview recording failed and so contemporaneous notes were used in this case in lieu of the recording. Interviews ranged from 16 to 48 min.

The three themes identified were as follows:

- The Aboriginal health workforce understood hepatitis B shame was common and mediated by poor health literacy, communication, and a lack of culturally safe spaces.
- The Aboriginal health workforce understood that the experience of hepatitis B shame was multifaceted, impactful, and perpetuated by intersecting stereotypes.
- The Aboriginal health workforce suggested pathways to improve hepatitis B care and reduce the impact of shame: utilise the Aboriginal health workforce more effectively, improve communication and culturally

safe spaces, emphasise community connection and reframe hepatitis B as a chronic condition.

1. The Aboriginal health workforce understood hepatitis B shame was common and mediated by poor health literacy, communication, and a lack of culturally safe spaces.

Hepatitis B related shame was reported to be pervasive and common in Aboriginal and Torres Strait Islander communities in the Top End of the Northern Territory by participants. This was often portrayed in the context of health literacy of the condition compared to other chronic conditions such as diabetes.

*“[Shame] is more than a common thing because they did know (sic) and heard a story about diabetes in the past and also heart disease and then only never knew or never heard about hepatitis B” (Participant 5).*

*“Oh, like out here, community, many people with hepatitis B that like – many people patient may feel shame” (Participant 8).*

The Aboriginal health workforce reported that such lack of hepatitis B health literacy mediated the experience of shame as it led to misconceptions of transmission routes, with many in community misattributing its acquisition as being predominantly sexual in nature.

*"I think it's got to do with having sex...that's more a shame job" (Participant 11)*

*"And people are being, like, hepatitis, automatically think it's from sex...So, most people will just think of it as a sexually transmitted infection" (Participant 12).*

One participant commented on ways in which hepatitis B was transmitted and alluded that the various forms of transmission were not understood more broadly in their community and ensuring people understood that there were more routes of transmission than just sexual modes could reduce shame.

*"So, as long as they understand that the – other ways – maybe there wouldn't be so much shame." (Participant 6).*

The Aboriginal health workforce reported different levels of health literacy surrounding hepatitis B among health care workers further contributed to confusion about hepatitis B in communities.

*"What I find really challenging is different doctors have different ideas about hepatitis B, and about pathology, and that's what causes so much confusion" (Participant 6).*

Poor health communication was also reported as contributing to shame by the Aboriginal health workforce as it caused people to feel frightened. This was founded in the inability to communicate in Aboriginal languages and in a culturally appropriate fashion. Aside from language, the way information was communicated, including through stories and visual arts, was also emphasised as lacking.

*"You have to give them like a clear picture...Not a medical term...Cause then they feel if you give them information in a medical term, then they feel frightened or ashamed, then they don't come to the clinic to have their checks." (Participant 13).*

The Aboriginal health workforce reported that the lack of gender appropriate health care directly led to experiences of shame and highlighted its importance in delivering culturally safe health care interactions. A barrier to providing such gender appropriate health care was the lack of male staff in Aboriginal and Torres Strait Islander communities in this region.

*"If it's a woman, they're not going to talk to a man... it's another cultural thing. They're not going to go to the clinic if there's all females...And I think it's a lot of shame around seeing a female, or a male and,*

*yeah...Maybe have a like- where you have a Men's Day or a Women's Day" (Participant 12).*

*"Need more male, male, male. We need male. A lot of us are women." (Participant 14).*

It was also noted by the Aboriginal health workforce that clinic visibility and the need to visit a clinic for care perpetuated feelings of shame. Indeed, poor health care utilisation was directly linked to concern about confidentiality from attending a clinic. This was a particular focus in smaller communities.

*"Yeah, there's a lot of shame to go to the clinic and things like that cause being in a small community, a lot of people talk...they don't want to be seen going to the clinic." (Participant 12).*

*"Cause if you are in the clinic with the doctor and the nurse, they might feel frightened or shame...It's best to go out and give the story outside. Then they feel comfortable." (Participant 13).*

2. The Aboriginal health workforce understood that the experience of hepatitis B related shame was multifaceted, impactful, and perpetuated by intersecting stereotypes.

The experience of hepatitis B related shame was understood by the Aboriginal health workforce to be multifaceted for individuals experiencing it. Their perception was that those living with hepatitis B had feelings of being at fault, of fear relating to transmission and of isolation from the community. The feelings of being at fault was illustrated in the following quotes:

*"They feel shame, worry and they feel confused. You know? And they – to them, they would feel – they would think that "What did I do wrong?" (Participant 14).*

*"And how it's passed on and it's no one's fault or anything like that. Just reassure them..." (Participant 12).*

The Aboriginal health workforce relayed that the fear of transmitting to others was also a common experience for those living with hepatitis B. This was again related to misconceived transmission routes including misattribution that hepatitis B could be passed on by sharing food and drink. The Aboriginal health workforce reported that community responsibility was of paramount importance in Aboriginal communities, and therefore a fear of transmitting to others was incredibly burdensome for the individual.

*"I guess people can feel a bit isolated if they do have it, in a way...so they feel, "well, I can't eat dinner at the table...I have to have one cup to myself....I know with my mob in our community, we don't want to pass it on, safe to say, our elders...they would probably feel there's a lot of weight on the shoulders, and they might just try to run away from it..." (Participant 15).*

In addition, there was an association with the clinic and diagnosis of a disease, and this created a barrier to accessing care.

*"They've got that disease and they think they – they don't want to go there, and they think they might get infect...like pass the infection to...some people think that if they come to the clinic, they might get diagnosed with other disease..." (Participant 13).*

The Aboriginal health workforce reported that isolation and the loss of community connection was a central component of hepatitis B related shame, as detailed in this quote:

*"Encourage them to come and they see that they are not alone...And we can go through the same direction....to help and support" (Participant 13).*

The Aboriginal health workforce noted that hepatitis B related shame had a significant impact on the health and wellbeing of individuals, was important to address, and emphasised it as a barrier to accessing healthcare. In the following two quotes, the participants emphasised the need to reduce shame and illustrated how shame stops people coming forward for care.

*"It's very shame...Reduce the worry. Reduce those feelings." (Participant 2).*

*"...shame and stigma...Just really getting rid of that in a way, because I think that's what stops people" (Participant 15).*

Intersecting stereotypes and discrimination experienced by Aboriginal and Torres Strait Islander people, as well as healthcare related stigma, was also noted by the Aboriginal health workforce as an issue facing those living with hepatitis B.

*"There's no point in having a lot of knowledge then the health care basically, excuse me, treat you like shit." (Participant 4).*

*"Like it's not that they don't care about their health, there's just like other things. Family obligations and things like that." (Participant 12).*

*"And a lot of stigmas I've had to break with my own work colleagues is that they can do it...just a bit more compassion – that's all. Can go a long way with our mob." (Participant 15).*

*"The staff can make you feel like an alien in your own place..." (Participant 10).*

As these quotes illustrated, the intersecting stereotypes were grounded in a lack of cultural safety and awareness of Aboriginal and Torres Strait Islander community and cultural obligations by healthcare providers. There was also a notable lack of flexibility in the delivery of health care in these contexts, and this perpetuated a disconnect between the priorities of the healthcare services and the needs of the community.

*"Non-Aboriginal people don't understand that Aboriginal people are busy – even though they don't have a job between 8:00 am and 4:30 pm – they just can't come to the clinic. You know, they have other things on like their cultural commitments..." (Participant 10).*

3. The Aboriginal health workforce suggested pathways to improve hepatitis B care and reduce the impact of shame: utilise the Aboriginal health workforce more effectively, improve communication and culturally safe spaces, emphasise community connection, and reframe hepatitis B as a chronic condition.

The Aboriginal health workforce noted a variety of ways to improve hepatitis B care and reduce the impact of shame. Central to this was the importance in improving health literacy. For instance, participants noted that the loss of connection, which results from a hepatitis B diagnosis, may be improved through education.

*"But I feel like if they had the right education, and the right information, then they could confide in someone...then they'd want to protect their family; and they'd want to protect their community because they are very community oriented." (Participant 15).*

The difficulties with medical communication and the way health communication needed to be tailored for Aboriginal and Torres Strait Islander people was highlighted and could improve understanding. The Aboriginal health workforce highlighted the need to use people's first language, as well as storytelling and use of visual arts.

*"Language is the most important thing, so do it in our languages as well, you know..." (Participant 11).*

*“Bring flip charts; visual, it’s got to be visual for people to fully understand or talk metaphorically.” (Participant 6).*

One participant, when explaining the importance of storytelling, explained that the story that hepatitis B was an ancient disease and came to Australia over fifty one thousand years ago, as demonstrated by genotypic analysis, was an important one to tell [28].

*“That story will help people understand and then we’ll tell them that story about this. It’s not new. It’s been here before. It’s been here long time ago.” (Participant 14).*

Central to ensuring more effective communication was to use the Aboriginal health workforce more effectively as this will ensure those living with hepatitis B understand the healthcare information provided. This was reported to go beyond language, emphasising the need to involve the workforce to ensure the information is presented in the correct way. Part of this was ensuring the collaboration between the non-Aboriginal and Aboriginal workforce, as illustrated in the following quotes.

*“...we have to be there as well so patient, and the doctor, and the Aboriginal health worker has to be there as well for the translation because that is the main thing...” (Participant 13).*

*“Keeping us in the loop and then we can share that information with our patients. And we can break down the information and share it in a way that we know they will understand.” (Participant 6).*

*“They wanted to learn more and find out and questioned me more. I have to go through the pictures, and the language, same time because some people – some clients, they are really confused what is the hepatitis B means. Yeah. I have to go through the steps you know...” (Participant 5).*

*“Particularly your health practitioners (sic) – Aboriginal – will be there as well, and Balanda (non-Aboriginal person). Working together.” (Participant 2).*

As discussed, the loss of connection to family and community was a key aspect in the experience of shame, that care provided needed to address this, and this was reported as a central role for the Aboriginal health workforce. The importance to emphasise to individuals that they were not isolated and to support them in their own environment was noted.

*“So, if they’ve got shame, we need to go to their house and sit with them; talk to them as a group. As a family...” (Participant 13).*

Despite this, there was noted to be poor utilisation and engagement of the skills and expertise of the Aboriginal health workforce in some clinics at the present time. A contributing factor to this was related to workforce shortage in these communities, requiring existing Aboriginal health workforce to take on multiple roles.

*“Utilise us AHPs (Aboriginal Health Practitioners) and us AHWs (Aboriginal Health Workers) more... Too many times we get used as drivers. But we feel the obligation to do that because there is nobody else there to do it, so some days you should. And I’m a receptionist. Like, I’m wearing all these hats in one day... Um – we don’t get utilised. Our skills aren’t being used. We – our voices aren’t being heard when we try and speak up for people.” (Participant 6).*

The Aboriginal health workforce also reported that increasing public health information visibility would improve education on transmission routes in general, and would reduce the misattribution of transmission routes, an important mediator of hepatitis B related shame.

*“I think we definitely need more information up in public areas about hepatitis and you know – you can be vaccinated against hepatitis. Hepatitis can’t be transmitted through kissing, smoking and sharing cups.” (Participant 10).*

The engagement of community and consultation with community leaders was central in ensuring such health messaging was delivered appropriately. One participant noted:

*“...definitely asking your community leaders – or who’s running the community, of course, about how is best we can get this message across, and just having them involved in like, say trainings and things as well...Listening to the community...that’s how you go somewhere...” (Participant 15).*

The Aboriginal health workforce reported that moving health care and health promotion into the community space and out of the clinic was a way in which care could be provided in a more comfortable and culturally safe area and reduce the occurrence and impact of shame. Gender specific health promotion was also noted to be needed in areas outside the clinic, and the need for more men to help in this area was emphasised.

*“But to encourage people to come in for a check-up – that’s my biggest battle out there all the time. And in their language. And in a different environment outside of the clinic would be good. Like um – in an environment which they feel more comfortable in. And – so it’s not so sterile. So, you can just sit and yarn and bring food.” (Participant 6).*

*“Specially like if, through the fields where the people are. Go there. Go to the field where the people is, you know... I need a volunteer up there. We need more men up there to educate. Specially in the fields” (Participant 2).*

Lastly, notwithstanding the need to address stigma related to sexually transmitted infections, the Aboriginal health workforce reported hepatitis B related shame could be reduced by contextualising hepatitis B with other chronic conditions, such as diabetes. This would mean it was part of any general health check and not specifically related to a sexual health check.

*“Whoever comes in, it’s not just for the hepatitis stuff, it’s for any health check-up, and then give them clear understanding” (Participant 13).*

## Discussion

There is limited information surrounding hepatitis B stigma, including in Aboriginal and Torres Strait Islander communities [2, 29]. To our knowledge, this is the first study which has examined the experience of hepatitis B related shame in Aboriginal and Torres Strait Islander communities in northern Australia, and has expanded on the knowledge gained from the only other Australian study of healthcare related hepatitis B stigma in Aboriginal and Torres Strait Islander communities [1]. Thematic analysis of the interviews has demonstrated that the experience of hepatitis B shame was impactful and related to feelings of fear of transmitting the virus to others, of being isolated, and of being at fault. The Aboriginal health workforce saw this issue as important to address and could improve hepatitis B care in this region.

Participants emphasised poor health literacy as a mediator of hepatitis B shame, and the lack of hepatitis B health literacy has been shown in other studies in northern Australia [13, 30]. For instance, there are many ways in which hepatitis B may be transmitted and is most often in early childhood in these communities [31]. Regardless, emphasis on its sexual transmission has led to feelings of shame regarding its acquisition, which has also been demonstrated with sexually transmitted infections in general [32]. This appeared to be mediated by health literacy regarding acquisition and should be seen as an important focus for future public health education.

Reframing of hepatitis B as a chronic infection, rather than a sexually transmitted infection, and embedding it within general health promotion campaigns, could be another suggestion for future policy development.

A study of young Aboriginal people found that being seen at a clinic for sexual health was perceived to lead to stigma and reputational damage, and the visibility of the clinic, appointment procedures and waiting times contributed significantly to this [33]. This issue was highlighted by the Aboriginal health workforce as being an issue for individuals seeking hepatitis B care in the Top End of the Northern Territory, with barriers including concerns about confidentiality and lack of gender specific spaces. These themes also emerged in qualitative studies exploring barriers to sexually transmitted infection testing [34, 35]. The creation of the “one stop liver shop” emphasised liver health rather than hepatitis B to diminish the impact of this issue [36]. The interviews demonstrated that care on country was important, and could facilitate culturally safe healthcare, leading to improved healthcare engagement. Avenues to operationalise such care could include investment in point of care testing, which would enable community delivered healthcare and has been shown to be effective for a variety of infections [37, 38].

The Aboriginal health workforce participants highlighted the central importance of communication in improving hepatitis B care and reducing the impact of shame. Inadequate communication has been shown to be pervasive in this region in relation to chronic disease care [39]. Central to this was language gaps in healthcare interactions, with the consistent use of interpreters previously shown to improve patient trajectories and self-discharge rates in hospitals [40]. It was similarly highlighted by the interviewees that communication in peoples’ first language would improve hepatitis B care. This may be difficult in some remote communities due to workforce shortages, with it previously shown that hospital interpreters were less likely to be used for Aboriginal minority languages [41]. A hepatitis B culturally appropriate app has been developed to try and overcome some of these challenges. This has only recently been translated into several languages, however the impact of this on health literacy and shame is not yet known and will be an important area for further investigation [19, 42, 43].

The different health literacy among healthcare providers had created confusion among people living with hepatitis B and the Aboriginal health workforce. Such differing hepatitis B knowledge is known to be a general issue among healthcare providers [1, 44]. Improving healthcare provider literacy may improve stigma, as seen in a study in New South Wales [1]. The benefit of specialised hepatitis B care delivered in partnership with community has been realised in this region with the “one stop

liver shop” improving the cascade of care to high levels [36]. The consultation paper for the fourth national hepatitis B strategy has concluded that building a comprehensive hepatitis B specific community and health workforce capacity has meant the Top End of Northern Territory is now leading in attaining national hepatitis B targets despite isolation challenges [45]. Current specific hepatitis B courses for the Aboriginal health workforce aim to continue to build and maintain this capacity and success and ensures consistency in hepatitis B related education [25, 26, 46].

Overcoming the disruption of connection to community was noted by participants to be extremely important while providing care for someone living with hepatitis B. The social and emotional wellbeing of Aboriginal and Torres Strait Islander people has been observed to be related to the connection of community, mind, body, country, and culture [47–49]. Placing emphasis on wellness and connection, rather than illness and reducing symptoms has been emphasised as central to effective clinical practice, and is mediated through the development of meaningful relationships [48]. Such patient centred approach was noted to be an effective avenue for reduction in stigma and empowered other stigma reduction programmes [50]. This requires the retention and involvement of Aboriginal health workforce in healthcare delivery as involvement of this workforce delivers culturally safe care, improves outcomes and counters stigma [1, 51]. It was noted by participants that Aboriginal health workforce skills were not being effectively utilised, often being used in other roles such as transport and administration due to workforce gaps. This is a common issue with recent declines in Aboriginal Health Practitioner staff, with the discriminatory rules and managerial practices for the Aboriginal workforce highlighted as key concerns in other studies [52, 53]. These concerns should guide wider health policy as there is an immediate need to increase and support this critically important workforce. Indeed, an increased Aboriginal health workforce is a specific goal of the Australia Health Practitioner Regulation Agency’s national strategy for cultural safety, and the interviews in this study have echoed the need to achieve this goal [23].

### Strengths and limitations

The strength of this study included a semi structured style of interviewing which allowed exploration of individual and community experiences from each participant’s perspective. We consulted Aboriginal investigators and the Menzies Infectious Diseases Indigenous Reference Group to ensure the research had the right methodology, and the collective knowledge we draw from this research will help inform how hepatitis B care is delivered in future.

Limitations include lack of involvement of people living with hepatitis B. While the perceptions we have presented may not be reflective of the actual experience of people living with hepatitis B themselves, we think the interviews of the Aboriginal health workforce has provided unique knowledge of the community, the feelings individuals experienced in being diagnosed with hepatitis B, and what care was available. Further study could examine these areas by interviewing those living with hepatitis B, after close coordination and consultation with the communities involved.

The inclusion of eight communities in the region, while numerous, is also not representative of all communities. While every community is unique, establishing common themes was intended to produce reciprocal benefits for all communities. This was summarised by one interviewee:

*“We don’t share – we don’t talk about what’s going really well; and one community, “You might want to try that here, it might work well for you”. You know? It would be good to have that” (Participant 6).*

General learnings drawn from these interviews would always only be intended to be applied in specific consultation with individual communities, respecting their individual identities.

### Conclusions

The experience of hepatitis B related shame is impactful in Aboriginal and Torres Strait Islander communities in the Top End of the Northern Territory. There are many components to hepatitis B related shame in these communities, and numerous factors contribute and perpetuate the experience. The Aboriginal health workforce has emphasised several pathways which would improve hepatitis B care and reduce the impact of shame, including improving communication and working more effectively with the Aboriginal health workforce and local communities.

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### Author contributions

RPS performed study concept and design, literature search, acquisition of data, performed analysis and interpretation of data and first draft writing, and revision of manuscript. SMB performed community education and liaison, analysis and interpretation of data and writing and revision of manuscript. PB performed study concept and design, literature search, project management, acquisition of data, and writing and revision of manuscript. KH performed study concept and design, literature search, acquisition of data and writing and revision of manuscript. PN performed community education and liaison, analysis and interpretation of data and writing and revision of manuscript. EVC performed project management, acquisition of data, and writing and revision of manuscript. MM performed project management and writing and revision of manuscript. GG performed community education and liaison, analysis and

interpretation of data and writing and revision of manuscript. AG performed analysis, and interpretation of data, and writing and revision of manuscript. JSD performed study concept and design, analysis, and interpretation of data, and writing and revision of manuscript. JD performed study concept and design, analysis, and interpretation of data, and writing and revision of manuscript. All authors approved the final manuscript.

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#### Data availability

No datasets were generated or analysed during the current study.

#### Declarations

##### Ethics approval and consent to participate

The Human Research Ethics Committee of Northern Territory Health and Menzies School of Health Research approved this study (HREC 2021–4037). This study was conducted in accordance with the Declaration of Helsinki, and the regulations and guidelines of the National Health and Medical Research Council [54, 55]. Informed consent to participate was obtained from participants.

##### Consent for publication

Not applicable.

##### Competing interests

The authors declare no competing interests.

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