Chronic hepatitis B

Care delivery and patient knowledge in the Torres Strait region of Australia

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Background
Chronic hepatitis B (CHB) disproportionately affects Indigenous Australians. This article reports the findings of two studies in the Torres Strait and Northern Peninsula area (T&NPA) of Queensland in Australia. The aim of the first study was to assess CHB care delivery, the second assessed CHB patient knowledge about the condition.

Methods
A pathology database search (1997–2009) identified a cohort of potential CHB patients in T&NPA. A file audit assessed care delivery for a random sample of 83 CHB patients. A survey assessed knowledge of 42 CHB patients.

Results
A total of 365 hepatitis B positive patients were identified. There are gaps in patient review, monitoring, follow up and specialist referral. Patients had limited knowledge about CHB and measures to reduce its health impact.

Discussion
Chronic hepatitis B affects a substantial number of Indigenous adults in the T&NPA. There is limited adherence to clinical guidelines. Improved uptake of clinical guidelines adapted for remote areas, incorporation of CHB into systematic chronic disease care, and culturally appropriate patient education resources and programs are needed.

Keywords
hepatitis B, chronic; health knowledge; delivery of health care

The Torres Strait and Northern Peninsula area (T&NPA) of remote north Queensland in Australia comprises 18 island communities and five communities at the top of Cape York Peninsula, with a total population of approximately 11 000 people, 83% of whom identify as Aboriginal and/or Torres Strait Islander.[1] (The authors acknowledge the diversity of Indigenous peoples in Australia and the problematic nature of attempting to adequately reflect that diversity with suitable terminology. In this article, the use of the term 'Indigenous', unless otherwise evident by the context of its use, should be taken to include Aboriginal and Torres Strait Islander peoples.)

Before the introduction of hepatitis B virus (HBV) vaccination in the mid 1980s, reported prevalence of chronic hepatitis B (CHB) in T&NPA was 11.5% in antenatal women and 10.6% in children.[2] Current regional prevalence is not known. Nationally, the prevalence of CHB in Indigenous Australians is estimated to be 2–8%, compared with 0.5–0.8% for the general Australian population.[3] Historically, HBV infection in Indigenous Australians has predominantly been acquired perinatally or in childhood,[4] with the infection likely to persist in 90% (when acquired perinatally) and 30% (when acquired in childhood).[5] Untreated CHB results in long term consequences – cirrhosis, hepatocellular carcinoma and liver failure – in 15–25% of patients.[5,6] Indigenous Australians sustain higher liver related mortality than non-Indigenous Australians, often associated with HBV.[7–9]

Growing evidence of the benefits from antiviral therapy for CHB patients,[10] the development of national clinical guidelines,[11] and the launch of the first Australian National Hepatitis B Strategy[3] triggered a regional review of CHB care and the development of CHB guidelines for rural and remote Queensland in 2010.[12] Australian studies of primary care management of CHB, including one in the T&NPA, demonstrate significant gaps in knowledge about CHB management among primary care providers.[13–16] In addition, low levels of knowledge of the disease have been reported in studies of Australian CHB patients, although none focused on Indigenous Australians.[15,17,18]

This article reports the findings of two studies in the T&NPA, the aim of the first was to assess CHB care delivery (2007–10), the second to assess CHB patient knowledge about the condition.

Methods

Data were retrieved from the single regional pathology provider for all people with positive hepatitis B surface antigen (hepBsAg) test results in the T&NPA, between June 1997 (when pathology reporting became computerised) and December 2009.

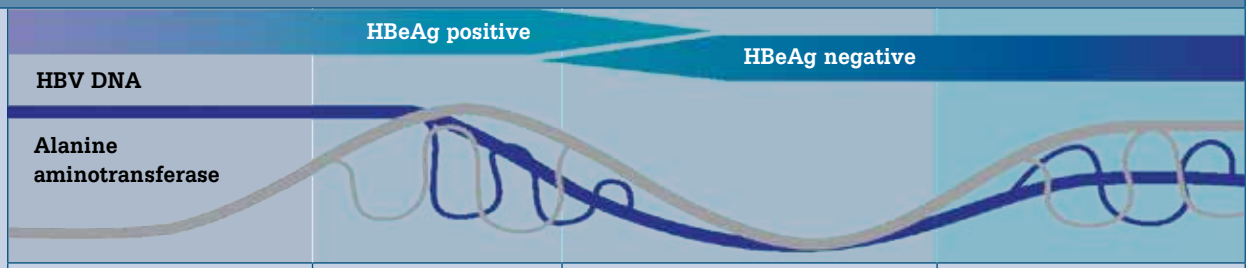
Chronic hepatitis B care delivery

A file audit was performed on a sample of the identified population of hepBsAg positive people, selected by random number generation. It assessed care delivery between 2007–10, with a focus on 2009–10. Audit eligibility was determined by T&NPA residence in 2010, and confirmation of CHB status. Pathology results from January 2007 to December 2010, patient medical records and specialist referral data systems were assessed. 2008 national guidelines[11] (*Table 1* and *2*) were adapted to develop audit standards (*Table 3*).

Chronic hepatitis B knowledge survey

A convenience sampling method was used. All identified residents with CHB aged more than 18 years from five communities were invited by letter, then telephone or home visit to participate; others were recruited when they attended CHB clinic appointments. A questionnaire was administered face-to-face in English, with Creole translation when needed, by a Torres Strait Islander health professional and a medical student. Each questionnaire took approximately 10 minutes.

Table 1. Chronic hepatitis B phases and suggested management of patients not receiving treatment



	Phase 1 Immune tolerance	Phase 2 Immune clearance	Phase 3 Immune control	Phase 4 Immune escape
HBsAg	+ for >6 months	+ for >6 months	+ for >6 months	+ for >6 months
HBeAg	+	+	–	–
ALT	Persistently normal	Persistently or intermittently elevated	Persistently normal	Persistently or intermittently elevated
HBV DNA*	≥20 000 IU/mL	Persistently or intermittently ≥20 000 IU/mL	<2000 IU/mL	Persistently or intermittently ≥2000 IU/mL
Liver histology	Minimal inflammation	Variable inflammation +/– fibrosis	Minimal inflammation and liver damage	Inflammation and often significant fibrosis
Natural history	Low risk of progression to advanced liver disease	Associated with hepatic flares and risk of progressive liver disease	• Low risk of advanced liver disease HBsAg loss: 1% per year • 10–20% have reactivation of HBV replication after many years	• Can enter this phase from immune clearance or immune control phase • High risk of progression to advanced liver disease
Suggested management	If ALT levels <2 times ULN (ULN = 30 U/L for men, 19 U/L for women): • No treatment • HBeAg and liver function tests every 12 months If ALT levels increase to >2 times ULN: • HBeAg and liver function tests every 3–6 months If ALT levels persistently >2 times ULN and if no HBeAg seroconversion within 6 months and/or age >40 years with ALT elevations 1–2 times ULN: • Consider referral to a specialist for consideration of liver biopsy and treatment	Consider referral to a specialist for consideration of liver biopsy and treatment	ALT level normal: • No treatment • HBV DNA and liver function tests every 12 months If ALT levels increase: • Check serum HBV DNA, exclude other possible causes of ALT elevation If HBV DNA >2000 IU/mL and/or persistent ALT elevation and no other cause found: • Consider referral to a specialist for consideration of liver biopsy and treatment	Consider referral to a specialist for consideration of liver biopsy and treatment

* HBV DNA assay is available on the Medicare Benefits Schedule once per year for untreated CHB patients and four times per year for treated CHB patients; ULN = upper limit normal; ALT = alanine aminotransferase

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Responses were tape-recorded. It assessed understanding of transmission and health effects of CHB, awareness of selected liver health protective behaviours and alcohol consumption.

Data analysis

Audit data were analysed using Stata (version 12). Chi-squared test was used to assess demographic differences between the audit and survey samples and the total identified hepBsAg positive population, and differences in liver function monitoring in 2007 compared with 2008–10. Chronic hepatitis B knowledge questionnaire data were collated and analysed in Microsoft Excel. The data were analysed descriptively using simple proportions.

Results

From June 1997 to December 2009, 380 people in the region had positive hepBsAg tests. An initial review excluded 15 people who had duplicate records, acute hepatitis B, or who had died. Of the 365 remaining, 50% (184) were female, 50% (181) were male. Thirty-eight percent (140) were less than 35 years of age (including 25 aged less than 25 years). Eighty-four percent (305) had a confirmatory hepBsAg test at least 6 months after their initial positive test.

Table 2. Criteria for referral to specialist and hepatocellular carcinoma screening in patients with chronic hepatitis B

Criteria for referral to a specialist

- If active disease (abnormal ALT, detectable HBV DNA level >2000 IU/mL [10 000 copies/mL], or evidence of chronic liver disease)

Or

- Suspicion of immunosuppression or advanced liver disease (even if ALT is normal and HBV DNA is low or undetectable)

Criteria for HCC surveillance (6 monthly ultrasound and alpha-fetoprotein test [AFP])

HCC surveillance is recommended in these HBsAg positive groups:*

- Asian men aged >40 years
- Asian women aged >50 years
- African people aged >20 years
- People with cirrhosis
- People with a family history of HCC

Consider HCC surveillance for patients with CHB if active disease (abnormal ALT, detectable HBV DNA level >2000 IU/mL [10 000 copies/mL], or evidence of chronic liver disease)

* There are no recommendations specific to Aboriginal and/or Torres Strait Islander peoples

Source: Decision making in HBV. Australasian Society for HIV medicine, 2010. Available at www.ashm.org.au/images/publications/PatientFactSheets/HBV/decision_making_hbv.pdf

Table 3. Clinical management standards assessed by audit

Pathology tests and monitoring

- Annual liver function tests (LFT)
- If ALT is more than twice the upper limit of normal (ULN), repeat LFT within 6 months
- HBV DNA test in 2009–10
- HCC surveillance (AFP and liver ultrasound) in 2009–10 if ≥40 years with ALT more than ULN and/or HBV DNA more than 2000 IU/mL
- Hepatitis A serology performed ever

Clinical management

- Medical officer review regarding CHB in 2009–10 (on at least one occasion)
- Documented assessment of alcohol use in 2009–10 (on at least one occasion)
- Review by liver team (gastroenterologist or viral hepatitis clinical nurse specialist) between 2007 and June 2011 if ALT more than ULN and HBV DNA more than 2000 IU/mL (on at least one occasion from 2007 to 2010)

Chronic hepatitis B care delivery

The audit sample (n=114) represented 31% of the 365 hepBsAg positive population. Thirty-one of the 114 were ineligible: 20 no longer lived in the region, six had died, two had acute hepatitis B, one duplicate patient, one seroconverted to hepBsAg negative, and one for whom no chart or recent results were available. Hence 73% (83) were audited. Pathology and medical record audit were completed for 79, the remaining four had pathology audit only as medical records were unavailable.

Demographics

The audited patients resided in 15 communities. Age and gender distribution were not significantly different from those in the overall hepBsAg positive population (p=0.4). Eighty-eight percent (73) were Torres Strait Islander, 6% (five) Aboriginal and Torres Strait Islander, 1% (one) Aboriginal, and 5% (four) were of other ethnicity (predominantly Papua New Guinean).

Adherence to recommended testing

Results are presented in *Table 4*. Thirty-seven percent (31) were hepBeAg positive. Although the proportion of patients who had liver function tests (LFT) performed every year (2007–10) was 25%, the proportion tested in any year from 2008 to 2010 (68–70%) was significantly greater than in 2007 (47%) (p=0.01). Six patients were diagnosed in 2008 or 2009, none of who had had a hepatitis B virus DNA (HBV DNA) test.

Specialist team review

Fifty-four percent (21 of 39) with abnormal alanine aminotransferase (ALT) results in

2008–10 had an HBV DNA test performed. Of these, 18 had HBV DNA >2000 IU/mL, 14 of whom had been reviewed by the specialist team.

Chronic hepatitis B knowledge survey

Forty-two resident Torres Strait Islanders with CHB (25 females, 17 males) participated. The sample had more females and was older than the overall identified hepBsAg positive population, but the differences were not statistically significant (p=0.41 for gender, p=0.5 for age). Respondents came from seven communities in T&NPA.

Hepatitis B virus/chronic hepatitis B knowledge

Four people identified vertical transmission, and one sexual transmission as the likely source of infection. Eighty-eight percent (37) were unaware how they became infected. There was some misinformation regarding transmission: two identified sharing food or drink and one suggested 'playing in dirty water' as a means of HBV transmission. Fifty percent (21) were aware that HBV affects the liver and 7% (three) identified the long term consequences of tumour or death. Overall, the responses indicated important gaps in knowledge of HBV/CHB.

Forty-three percent (18) reported having received advice on how to stay healthy with CHB, and most of these referred to the need for a healthy diet. Fifty-seven percent (24) could not identify any health protective behaviours unprompted (*Table 5*).

Fifty-two percent (22) reported that they drank alcohol. Eighteen reported drinking at least fortnightly, and most who drank alcohol (21 of 22) reported drinking at harmful levels on any drinking day.

Table 4. Chronic hepatitis B care delivery in T&NPA – audit findings

	Number (%)
Pathology tests and monitoring	
Annual LFT 2007–10*	21/83 (25)
ALT more than twice the ULN 2007–10** – repeat LFT within 6 months#	18/83 (22) 4/18 (22)
HBV DNA test performed 2009–10**	25/83 (30)
Hepatitis A serology ever – hepatitis A immune	33/83 (40) 32/33 (97†)
HCC surveillance 2009–10**^	5/24 (21)
Clinical management	
Medical officer review regarding CHB 2009–10**	28/79## (35)
Documented discussion of alcohol use 2009–10**	35/79## (44)

* Or since diagnosis if diagnosed after 2007
** On at least one occasion
# For people with ALT more than twice the ULN
† Percentage of those tested. The one person tested who was not immune to hepatitis A had not received hepatitis A vaccination
^ AFP and liver ultrasound for people aged ≥40 years with ALT > ULN and/or HBV DNA >2000 IU/mL
Medical records were available for 79 people

Table 5. Chronic hepatitis B patient survey: awareness of selected health protective behaviours in relation to chronic hepatitis B

	Number aware (unprompted)	Number aware (prompted)	Total number aware (n=42) (%)
Need for regular check-ups	2	0	2 (5)
Limit alcohol use	7	8	15 (36)
Avoid sharing razors	5	1	6 (14)
Use condoms	1	3	4 (10)
Immunise family contacts	0	0	0 (0)

Discussion

These studies complement assessments of health system arrangements and CHB knowledge among healthcare providers in the region, which found significant gaps in practitioner knowledge and lack of a recall system or a model of care for CHB.[13] Together they provide an overview of the challenge posed by CHB in T&NPA today. The most important strategy to reduce CHB and its sequelae is an effective infant immunisation program,[3] but comprehensive care for those with CHB is also important. The extremely high regional prevalence of obesity and diabetes,[19] and levels of reported alcohol consumption,[20] may potentiate CHB related liver damage.[6] The number of young people with CHB is a cause for concern, especially in those born since the introduction of vaccination.

Delivery of CHB care was broadly consistent with that found in general practice settings elsewhere in Australia,[14] with some improvement in T&NPA since 2007, although the need for more timely and comprehensive responses to abnormal results remains.

Factors contributing to the gaps in care may include ineffective uptake of regionally adapted clinical guidelines integrated into practice, insufficient workforce development and inadequate patient information and recall systems.[13–16,21] In addition, remoteness, cultural factors (including health priorities),[22] costs (personal and to the health system) and an often transient workforce may affect care delivery.[13] The audit findings suggest a need for better dissemination of developments. For example, 53% of patients aged ≥40 years had surveillance for HCC in 2009–10 using alpha-fetoprotein test (AFP); whereas, despite government funding

for annual HBV DNA testing since mid 2008,[23] there was limited uptake, including among those newly diagnosed or with abnormal liver function. Hepatitis B virus DNA testing in remote areas requires particular diligence in specimen management,[24] which may represent a barrier to testing. Similarly, access to radiology for remote communities presents logistic and financial challenges. Mobility to and from the region was notable in this cohort and could affect follow up. The findings support the contention that CHB care should be moved from a sexual health framework (as in T&NPA at present) to one in which it is understood and managed as a chronic disease.

The CHB knowledge survey found a low level of knowledge about CHB and a lack of awareness of important health protective behaviours, including moderation of alcohol use. Strategies and culturally appropriate resources to improve patient education are needed.

The 365 hepBsAg positive patients from whom the audit sample was drawn cannot be assumed to represent the total current CHB population in the region. Determination of the latter would be affected by test coverage, deaths and migration. In addition, a small proportion of the hepBsAg positive population would have acute hepatitis B. In relation to testing coverage, the patients identified are likely to represent a substantial proportion of those with CHB because of an awareness of historically high regional prevalence, and recommendations for testing in adult and sexual health checks.[12] Of the 60 people without a confirmatory hepBsAg result, the majority would be likely to have CHB.[25]

Regarding preventive care related to hepatitis A, we sought documentation of immunity, then a record of vaccination for those found to be non-immune, consistent with recommendations for populations with endemic levels of hepatitis A.[26,27]

There are a number of limitations in these studies. Medical record review may have underestimated care delivered, as only records in the primary care clinic were assessed; care delivered but not recorded, or delivered elsewhere would not have been captured. We did not seek family history of HCC. Although a recognised risk factor for complications (and hence indication for consideration of HCC surveillance), the number with a family history would have been small, and family history documentation has been shown to be poor.[14] The number warranting liver team review remains uncertain because of limited liver function and HBV DNA testing.

The CHB knowledge survey sample, representing 12% of the identified hepBsAg positive population, was not randomly selected. Thus, the findings may not be representative of the CHB population in T&NPA. The recruitment method is likely to have resulted in bias toward greater connection to the health system, which might suggest increased likelihood of CHB awareness. The survey questionnaire focused on a bio-medical understanding of CHB, and it would be informative to develop a better understanding of people's cultural perception of the disease. Though a limited sample, the findings highlight a need for increased education about CHB.

Conclusion

There are considerable numbers of people with CHB in the T&NPA, yet adherence to guidelines for delivery of CHB care is limited, and patient knowledge of the disease, its complications, and health protective behaviours among those surveyed is poor. Until the HBV vaccination program reduces rates of CHB in Indigenous Australians, screening for CHB (as per the National Hepatitis B Testing Policy[28]) and more effective follow up of those identified with the disease are required. There is a need for better uptake of guidelines adapted for remote areas, staff and patient education, and implementation of systematic care in a chronic disease framework. Without such measures, patients with CHB will continue to experience preventable liver related morbidity and mortality for some decades.

Implications for general practice

- Despite the introduction of infant vaccination, CHB affects many Indigenous Australian adults.
- All Indigenous Australians should be offered testing for CHB once in adult life.
- A diagnosis of CHB requires a systematic approach to patient care, as for other chronic diseases.
- Regular review and monitoring allows modifiable risk factors to be addressed and identification of patients in an active phase of CHB who may benefit from therapy.
- It is likely that many Indigenous Australian CHB patients require better education about their condition.

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