



Respect your liver

Exploring the Victorian Aboriginal community's perceptions of viral hepatitis and liver cancer

Priority Populations

Cancer Council Victoria

June 2015

Sexual Health Team

**Victorian Aboriginal Community Controlled
Health Organisation**

Where the term Aboriginal is used in this report, it is inclusive of Aboriginal and/or Torres Strait Islander Peoples.

Executive summary

Respect your liver is a partnership project between Cancer Council Victoria (Cancer Council) and the Victorian Aboriginal Community Controlled Health Organisation (VACCHO). VACCHO and Cancer Council acknowledge the traditional owners of the land across Victoria on which the consultations with community members took place.

This project sought to understand perceptions of viral hepatitis and liver cancer in Victorian Aboriginal communities. Community consultations explored perceptions and shame around identifying and disclosing, as well as barriers to care and treatment. Understanding of the management of hepatitis B and C, liver cancer and preventative measures were also explored.

In Australia there are 450,000 people estimated to have a viral hepatitis infections. The Australian Institute of Health and Welfare (AIHW 2014) predict that compared with the non-Aboriginal population, Aboriginal Australians have three times the population-based incidence rate of hepatocellular carcinoma and are three times more likely to die of liver cancer.

In Australia there are over 218,000 people living with chronic (long-term) hepatitis B, more than 20,000 are Aboriginal Australians. There is also an estimated 230,000 people living in Australia with chronic hepatitis C infection. This includes 80,000 with moderate to severe liver disease. However the rate of diagnosis of hepatitis C antibody in the Aboriginal Australian population was more than three times the rate in the mainstream population in 2013.

This exploratory project consulted 73 Victorian community members, Aboriginal Health Workers (AHWs) and other health professionals working in the Aboriginal community controlled health sector. The key themes arising from the discussions were: Identifying shame; Diagnosis; Treatment; A health system with low levels of cultural safety; Gaps in cultural safety amongst some health professionals and Hepatitis and liver cancer education.

Shame

Examples provided in relation to the shame and perceptions of hepatitis B, hepatitis C and liver cancer included:

- Raised questions about the cause and transmission of hepatitis B&C, including an association with AIDS
- Stigma around drug use and by implication drug users (hepatitis C) and an unhealthy lifestyle *“If people don’t want to change their habits they are not going to worry about Hep C”*
- Too shamed to tell
- Alcohol and drugs damage the liver
- People don’t know that hepatitis B&C can turn into liver cancer if untreated
- Denial – *“once they know, not going to do anything about it, seem to think it will go away...”*
- Fear about it being the “C” word, cancer is scary and a death sentence

Diagnosis and Treatment

The most common comment in relation to diagnosis was an acknowledgement that signs and symptoms of hepatitis are not known or understood and not always present.

A number of community members and health workers were not aware that hepatitis B can be prevented (through immunisation) or managed when people were tested positive or that hepatitis C can be treated.

A number of health professionals working with the Aboriginal community commented on factors that hinder treatment for hepatitis C, including people who chose not to have treatment because it would impact on their ability to look after their family.

Where the term Aboriginal is used in this report, it is inclusive of Aboriginal and/or Torres Strait Islander Peoples.

- One General Practitioner commented on the long term consequences of having viruses and waiting for new treatments. *“It is difficult to give clear messages in this context especially when people are thinking it might progress to liver cancer while waiting for a new treatment”*.

Access to treatment clinics was identified as a significant barrier to receiving treatment. Travelling for rural Victorians was prohibitive along with long waiting lists at clinics. The importance of having a support person when visiting a doctor or specialist was raised a number of times.

Emotional and social well-being

Generational grief and trauma was identified as a factor around self-medication with drugs and alcohol. The message clearly was that this cycle of grief from the stolen generations and trans-generational grief needs to be addressed.

Cultural safety

The need for the health system to be more culturally safe and the impact of institutionalisation continues to be a significant barrier for Aboriginal people attending large clinics.

The need for doctors to receive cross cultural safety training was identified a number of times by community members and health workers, “...think they’d had it by now hey?”

Many examples were shared about the discrimination that the Victorian Aboriginal community face from some health professionals and the reluctance to be continually subject to this within the health system in order to manage their health issues. Having Aboriginal Hospital Liaison Officers was considered a way to help “bridge the gap”.

Education

The need for professional development for doctors was also raised in order to increase: their knowledge; improve their communications with patients about viral hepatitis and liver cancer; and viral hepatitis testing. Community members were also keen to increase their knowledge and awareness in relation to viral hepatitis and liver cancer.

Introduction

We recognise that a potentially preventable disease such as liver cancer, can have a significant impact on the Victorian Aboriginal community given the higher incidence and mortality rates than in the non-Aboriginal community.

Respect your liver is a partnership project between Cancer Council Victoria (Cancer Council) and VACCHO in consultation with the Victorian Aboriginal community.

Aboriginal and/or Torres Strait Islander Peoples* have a higher risk of viral hepatitis. Factors contributing to the risk of liver cancer include:

- Many people don't know they have viral hepatitis, particularly chronic hepatitis B
- Most people don't have any symptoms of hepatitis B or C, yet liver damage can still happen
- Many people with chronic hepatitis B and C are unaware of the importance of ongoing monitoring of their condition
 - Less than 1% accessed treatment for hepatitis C annually
 - Less than 5% are being treated for hepatitis B annually
- The complexity of co-morbidities together with low socio-economic levels and poor access to health care
- The complexity of lifestyle factors that impact on prevention and treatment for hepatitis

There is qualitative research (NCHSR: 2012) to suggest that issues of stigma are hindering discussion around chronic hepatitis B (CHB) and hepatitis C and its prevention, treatment and management. Confusing CHB with other forms of hepatitis including hepatitis A and C has led to a perception that CHB is linked primarily with injecting drug use and poor sexual health. Anecdotal evidence suggests that little is understood about liver cancer and the potential to prevent it through hepatitis B vaccination and management, and the treatment of hepatitis C.

Where the term Aboriginal is used in this report, it is inclusive of Aboriginal and/or Torres Strait Islander Peoples.

Background

In Australia there are 450,000 people estimated to have a viral hepatitis infections. The Kirby Institute (2014) estimate that nationally the number of people dying from complication relating to CHB is predicted to increase from 450 per year (2008) to 1,550 per year in 2017.

AIHW (2014) predict that compared with the non-Aboriginal population, Aboriginal Australians have three times the population-based incidence rate of hepatocellular carcinoma and are three times more likely to die of liver cancer. This reflects a higher burden of chronic liver disease in Australian Aboriginal populations, including high rates of chronic hepatitis B viral infection.

In Australia there are over 218,000 people living with chronic (long-term) hepatitis B and more than 20,000 are Aboriginal Australians.

There is an estimated 230,000 people living in Australia with chronic hepatitis C infection. This includes 80,000 with moderate to severe liver disease. The rate of diagnosis of hepatitis C antibody in the Aboriginal Australian population was more than three times the rate in the mainstream population in 2013.

The estimated number of people living with moderate to severe liver disease has more than doubled (115% increase) over the past ten years. An estimated 630 (400 – 880) deaths attributable to chronic hepatitis C infection occurred in 2013.

Project approach

The project approach and refinement of the aims and objectives was guided by the literature and the exploratory consultations with community.

Project aim

This project sought to understand perceptions of hepatitis and liver cancer in Victorian Aboriginal communities. Community consultations explored perceptions and shame around identifying and disclosing, as well as barriers to care and treatment. Understanding of the management of hepatitis B and C, liver cancer and preventative measures were also explored.

It is anticipated that the outcomes of the consultations will inform the development of culturally appropriate health promotion messages and engagement with the Victorian Aboriginal community in order to decrease hepatitis related liver cancer.

Project objectives

- 1) To identify the perceptions amongst the Victorian Aboriginal community of:
 - The significance of liver cancer
 - Hepatitis B and C (including prevention and transmission)
 - The cause of liver cancer
 - How liver cancer can be prevented
 - Link between viral hepatitis and liver cancer
- 2) To identify community attitudes through the experience of Aboriginal Health Workers and health professionals working with the community, in relation to:
 - The significance of liver cancer
 - Hepatitis B and C (including prevention and transmission)
 - The cause of liver cancer
 - How liver cancer can be prevented
 - Link between viral hepatitis and liver cancer
- 3) To explore practical strategies to address issues associated with hepatitis B and C and liver cancer.

Where the term Aboriginal is used in this report, it is inclusive of Aboriginal and/or Torres Strait Islander Peoples.

Literature briefing

A brief review of the literature included reference to national and state focused initiatives with Aboriginal communities. The literature informed the exploratory consultations which in turn revised the community consultations.

Viral hepatitis statistics

Hepatitis Victoria reports that almost 500,000 people in Australia, or 2% of the population, live with chronic viral hepatitis (hepatitis B and C). This is over 17 times the number of people living with HIV/AIDS. 15,000 Australians are diagnosed with viral hepatitis each year - around the same number diagnosed with breast cancer.

Nearly 1,000 Australians die each year from hepatitis B and C. Liver cancer largely caused by chronic viral hepatitis infection is the fastest increasing cause of cancer death in Australia (MacLachlan & Cowie 2012).

The Kirby Institute (2014) estimate that nationally the number of people dying from hepatitis B infection is predicted to increase from 450 per year (2008) to 1,550 per year in 2017.

Without intervention, it has been estimated that by 2017 the incidence of liver cancer in Australia attributable to hepatitis B will be three times that seen in 2008. Untreated chronic hepatitis B can lead to cirrhosis and liver cancer for up to 25% of people with the virus.

AIHW (2014) predict that compared with the non-Aboriginal population, Aboriginal Australians have three times the population-based incidence rate of hepatocellular carcinoma and are three times more likely to die of liver cancer. This reflects a higher burden of chronic liver disease in Australian Aboriginal populations, including high rates of CHB viral infection.

In Australia there are over 218,000 people living with chronic (long-term) hepatitis B and more than 20,000 are Aboriginal Australians.

There is an estimated 230,000 people living in Australia with chronic hepatitis C infection. Between 60–70% of those with chronic HCV infections will develop chronic liver disease, 20–30% will develop cirrhosis and 1–5% will be diagnosed with hepatocellular carcinoma (HCC), the most common form of liver cancer (Thompson Coon J et al (2007),

The estimated number of people living with moderate to severe liver disease has more than doubled (115% increase) over the past ten years. An estimated 630 (400 – 880) deaths attributable to chronic hepatitis C infection occurred in 2013.

Not everyone with hepatitis B will need treatment, however less than 5% of people of those who are require it are currently receiving antiviral treatment. Less than 2% of people with hepatitis C seek treatment each year. To have any impact on health outcomes, the National Hepatitis Strategies identify that hepatitis B treatment rates need to increase to at least 15% and hepatitis C rates need to increase by 50% each year.

In addition, 3-5% of Australian prisoners have CHB and between 30-40% of Victorian prisoners have chronic hepatitis C (CHC). With an over representation of Aboriginal people in the prison system, these figures have a significant impact on Aboriginal people in Victoria.

Where the term Aboriginal is used in this report, it is inclusive of Aboriginal and/or Torres Strait Islander Peoples.

Literature findings

Shame

With the focus of this project exploring shame and perceptions of viral hepatitis and liver cancer as well knowledge about the cause of viral hepatitis, treatment and management, it is important to consider the concept of shame from an Aboriginal perspective. McNally describes this clearly.

“Shame for Indigenous Australians has distinct cultural meanings; it cannot be characterised as guilt or embarrassment alone. Shame incorporates negative ways of being perceived by others, both inside and outside the community. Shame impacts on how a person is received and treated. Shame and shyness, which are intrinsically linked, do influence people’s interactions with health workers. The workings of shame have implications on health and health care outcomes and are evident in the various barriers to accessing hepatitis C care and treatment.” (McNally 2009:21).

The findings from the McNally (2009) report revealed, “shame associated with hepatitis C has stopped health workers talking about hepatitis C and stopped people accessing information about hepatitis C.”

“Many health workers and community workers noted that there are simply too many barriers to treatment. The challenges associated with poverty, poor access to health care in cities, regional and remote settings, the high morbidity for some Indigenous people and the high consumption of alcohol and drugs appear overwhelming. But the greatest challenge is finding ways to deal with the shame.” (McNally 2009:22).

Linked to the notion of shame, McNally’s findings also identified the challenges Aboriginal people have when accessing Aboriginal health services where members of their community work. Many Aboriginal people reported choosing not to tell about their private life because of the shame felt. It was considered wrongful and humiliating given the health care workers were living in their community and often times a relative.

Hepatitis B

The Australian National Hepatitis B Strategy 2010-13 outlined five priority areas in which to develop a comprehensive response to hepatitis B virus (HBV). This included:

- Building partnerships and strengthening community action
- Preventing HBV transmission
- Optimising diagnosis and screening
- Clinical management of people with CHB
- Developing health maintenance, care and support for people with HBV

Olsen et al (2014) in a response to this national strategy identified “Significant gaps in knowledge and practice in relation to each of the five National Hepatitis B Strategy priority action areas”.

However, in response to preventing HBV transmission, Olsen highlighted the effectiveness of antenatal screening for HBV in Aboriginal women at 91-98%. The introduction of universal vaccination for all infants in Australia in 2000 show that HBV immunisation coverage of Aboriginal children nationally was just under 97% (Menzies et al 2008 & Hull et al 2010).

The National Hepatitis B Needs Assessment (2007) highlighted the low priority of HBV in health services and communities where other social contexts are more prevailing and where there are competing health priorities.

Where the term Aboriginal is used in this report, it is inclusive of Aboriginal and/or Torres Strait Islander Peoples.

The Needs Assessment identified that initiatives such as a Well Person's Health Check, implemented through the Aboriginal Medical Services have the potential to increase screening and diagnosis of HBV. The assessment identified however that there is little data in relation to testing practices or best practice in providing a hepatitis B diagnosis.

Although the importance for people to be accessing clinical management services to reduce the burden of CHB leading to cirrhosis, hepatocellular carcinoma and liver failure is acknowledged, Olsen et al (2014) found only one article that reviewed clinical management practice. An audit conducted by Preston-Thomas et al (2013) in the Torres Strait and Northern Peninsula revealed that over a four year period, only 25% of patients with CHB had received a liver function test, and across two years only 35% had received a medical officer review regarding CHB and only 44% had a documented discussion about alcohol use.

Further work undertaken by Wallace et al (2014) in the Torres Strait Island region and northern Australia documented how health services respond to CHB. Two significant issues were raised:

- The absence of a systems-based approach to clinically managing the infection
- Variable knowledge about the infection by the health workforce

Other issues the report identified were:

- Competing and more urgent health priorities
- The silent nature of CHB infection at an individual and systems level
- Inadequate resources
- Transient health workforce

Other studies have also identified that late diagnosis, poor access to care and a higher prevalence of co-morbidities (including diabetes, kidney and other diseases) can compromise treatment and/or result in poorer outcomes (Homewood et al 2005 and Roder 2005, 2007).

The Needs Assessment highlighted that Aboriginal Medical Services (AMSs) should be provided with additional information and training to respond to the clinical needs of people with CHB. Factors such as remoteness, co-morbidities, shorter life expectancy and cultural issues must be considered when developing guidelines for primary health-care providers dealing with CHB in Aboriginal health settings (Fisher and Huffman 2003).

Condon et al (2003) in a review of Cancer in Aboriginal Australians highlighted that major improvements in preventive services, screening, primary care and specialist treatment services are required to reduce cancer incidence and improve cancer outcomes for Australian Aboriginal people.

Low knowledge levels among health-care staff and those with CHB was identified by Davies et al (2014) as a major barrier to increasing levels of awareness in communities. Davies undertook interviews to explore hepatitis B related knowledge, perceptions and experiences of Aboriginal people in remote settings and their health care providers. The key findings identified:

- There was a distinct lack of biomedical knowledge regarding CHB in people living with CHB
- Many misconceptions about hepatitis B exist, especially in relation to causation and transmission

Where the term Aboriginal is used in this report, it is inclusive of Aboriginal and/or Torres Strait Islander Peoples.

- Confusion exists between Human Immunodeficiency Virus (HIV) and CHB with some community members reporting that the two diseases were “one and the same sickness”. This was reported to contribute significantly to the sense of stigma or shame around a diagnosis of CHB and that it had to be kept a secret because of what it might reveal about sexual orientation or partner preference. An element of individual blame for acquiring CHB was reported as centering around awareness that CHB could be sexually acquired.
- Health practitioner (Aboriginal and non-Aboriginal) knowledge was also low

The key findings in relation to community perceptions included:

- “It’s like a silent killer” (hepatitis B)
- Scary sickness
- Fear – either pushed people to take their tablets and prevent imminent death or made them too afraid to attend the clinic

Hepatitis C

A research project exploring barriers to hepatitis C treatment in Aboriginal communities in Victoria, reported limited knowledge about the hepatitis C virus as a key barrier preventing people from accessing care and treatment. Some people were not aware that treatment was an option. Again, like CHB, this report revealed there is a lack of knowledge amongst health care workers and by community members in relation to the hepatitis C virus (McNally, 2009).

The Fourth National Hepatitis C Strategy 2014-2017 has highlighted that specific efforts are required to improve health promotion activities and the use of harm reduction strategies. It also identified the high levels of stigma and discrimination, socio-economic difficulties for people in rural and remote communities and the disproportionate rate of incarceration of Aboriginal and Torres Strait Islander people. There is also significant support for the use of peer education in these communities, with evidence that Aboriginal people prefer obtaining injecting equipment from known friends and others (Bryant, J. and Hopwood, M. 2009).

The strategy states that models developed to increase the involvement of primary health care providers and other services should include Aboriginal community controlled health services (ACCHSs) and other specific Aboriginal services.

The strategy outlines a number of priority action areas for 2014-2017. Those most pertinent to the themes discussed in this exploratory study are listed below.

Prevent:

- Increased access and availability of sterile injecting equipment and access to opioid pharmacotherapy programs
- Build knowledge and skills in priority populations, healthcare professionals and the community on hepatitis C transmission, risks, testing and treatment.

Test:

- Increase testing of hepatitis C in priority populations
- Improve referral and access to high quality support services at the time of diagnosis for people with or at risk of hepatitis C to initiate a pathway to care

Management, care and support:

- Improved awareness and knowledge in priority populations about treatment options
- Implement strategies to encourage the involvement of health care professionals in shared care models for people with hepatitis C

Where the term Aboriginal is used in this report, it is inclusive of Aboriginal and/or Torres Strait Islander Peoples.

- Implement strategies to encourage increased involvement of local health care networks to ensure better integration of services

Workforce:

- Governments and community organisations to increase awareness and understanding of hepatitis C, reduce stigma and discrimination and improve access to services
- Increase primary health care engagement in hepatitis C testing, management and treatment
- Enhance the capacity of education and service providers to engage with people with or at risk of hepatitis C infection and provide targeted education and health promotion intervention

State and National policies

This project aligned with the current priorities and objectives of State and National policies including:

Koolin Balit 2012 – 2022 (Department of Health and Human Services)

Objectives:

- close the gap in life expectancy for Aboriginal people living in Victoria
- improve access to services and outcomes for Aboriginal people
- Focusing on the priority areas

Priorities:

- Addressing risk factors
- Managing illness better with effective health services

Second National Hepatitis B Strategy 2014 -2017 (Department of Health)

- Increase the proportion of people with chronic hepatitis B who have been diagnosed
- Increase access to appropriate management and care for people with chronic hepatitis B
- Eliminate the negative impact of stigma, discrimination, and legal and human rights issues on people's health.

Fourth National Aboriginal and Torres Strait Islander Blood-borne Viruses and Sexually Transmissible Infections Strategy 2014–2017 (Department of Health)

- Increase the number of Aboriginal and Torres Strait Islander people with BBV receiving appropriate management, care and support for BBV.
- Eliminate the negative impact of stigma, discrimination and human rights issues on Aboriginal and Torres Strait Islander health.
- Increase engagement with Aboriginal and Torres Strait Islander communities through sustained and authentic action.
- Improve the delivery of and access to appropriate services.

Fourth National Hepatitis C Strategy 2014-2017 (Department of Health)

Objectives:

- Reduce the burden of disease attributed to chronic hepatitis C
- Eliminate the negative impact of stigma, discrimination, legal and human rights issues on people's health.

Where the term Aboriginal is used in this report, it is inclusive of Aboriginal and/or Torres Strait Islander Peoples.

Exploratory consultations

Exploratory consultations took place with key stakeholders to discuss the project outline and to guide the development of the project plan. Exploratory discussions took place with:

- Victorian Aboriginal Community Controlled Health Organisation
- Victorian Aboriginal Health Service
- Hepatitis Victoria
- Victorian Viral Hepatitis Educator
- Njernda Aboriginal Corporation
- Cancer Council Victoria

Engaging respectfully with community

An Aboriginal consultant was engaged to work with the project coordinator to facilitate the consultations with community members and health workers. This provided a valuable connection with each community, respectfully acknowledging that engaging Aboriginal people in a project creates a structure for successful engagement with the community.

Each of the consultations with community included the provision of a lunch and healing stones as an acknowledgement of the contribution from each group.

Community/health worker consultations

Consultation with the community and AHWs was the key focus of this project. This was undertaken in accordance with the protocols and ethics employed when undertaking projects within the Aboriginal community. Based on this approach the project team was guided and supported by each community to yarn directly with that community or via the health workers associated/involved with it.

Sample

Existing community/health worker groups and meetings were utilised to reduce the impact of the consultation process on the community. One health worker group arranged a separate meeting for the consultation to occur.

Apart from one community group which was a women's chronic disease group, all consultations were open to men and women. Utilising the existing Koorie Maternity Services worker forum, meant that this was also an all-women's group by default.

Six communities and/or meetings were identified for the consultations. These included two rural and three metropolitan groups and a state wide group. In addition to the exploratory consultations, 73 people were consulted, 27 community members and 46 Aboriginal and non-Aboriginal health workers. Each group is listed below:

- Echuca – Njernda Aboriginal Corporation
- Albury/Wodonga – Mungabareena Aboriginal Corporation & Albury Wodonga Aboriginal Health Service and services in the surrounding districts
- Thornbury – Gurwidj, Aborigines Advancement League (women's group)
- Fitzroy - Victorian Aboriginal Health Service (one community and one medical/AHW meeting)
- State wide Koorie Maternity Service workers forum

Where the term Aboriginal is used in this report, it is inclusive of Aboriginal and/or Torres Strait Islander Peoples.

Table 1. Consultation sample

Target group	Women	Men	Rural	Metropolitan	Total
State wide Koori Maternity Service workers forum	15	0	√		15
Gurwidj - Women's chronic disease group	12	0		√	12
Njernda Aboriginal Corporation health workers	5	0	√		5
Albury/Wodonga & districts Aboriginal Health Workers	12	1	√		13
Victorian Aboriginal Health Service community meeting	13	2		√	15
Victorian Aboriginal Health Service medical meeting	9	4		√	13
7 consultations	66	7			73

Where the term Aboriginal is used in this report, it is inclusive of Aboriginal and/or Torres Strait Islander Peoples.

Overview of Findings

Facilitated discussion was based around the project objectives and sought to identify and understand community perceptions, shame factor and knowledge around hepatitis and related liver cancer. The key themes arising from the discussions were:

- Identifying shame around hepatitis B & C and liver cancer
- Diagnosis – lack of symptoms, competing priorities
- Treatment – geographical barriers to access and side effects of treatment
- A health system with low levels of cultural safety
- Gaps in cultural competence amongst health professionals
- Hepatitis and liver cancer education

Each of these key themes is discussed in more detail below.

Shame

When asked about what the Aboriginal community think when they hear the words: hepatitis B, hepatitis C and liver cancer, the following responses were provided by community members and perceptions from health workers working with community. The consultations were purposefully with the general community to understand the broader community perceptions and not specifically with community members diagnosed with hepatitis.

Hepatitis B

- An association or query about the association with AIDS
- Raised questions about the cause – how someone gets Hepatitis B
- Comments about not seeing hepatitis B in the community
- Comments about children being immunised for hepatitis B
- Perceptions people can be “worry-free” because they had the vaccination
- “Think about how will it affect me, illness, sickness, it’s liver disease, you’d be scared and in shock”. “You think of death and depression. Terrible for the family, especially if the person is the back bone of the family”.
- Individual comments about:
 - Germs
 - Dirt in your blood

Overall, there was less of an understanding about hepatitis B compared to hepatitis C and in many instances a lack of knowledge about the difference between hepatitis B and C.

Hepatitis C

- A stigma around drug use and by implication drug users
- Drugs and alcohol
- Unhealthy lifestyle
- Transmission and questions about how viral hepatitis is transmitted
- Some health workers reported seeing a lot more cases of hepatitis C

Liver Cancer

- Alcohol and drugs damage the liver
- Drinking plays a big part
- Playing around sexually

Where the term Aboriginal is used in this report, it is inclusive of Aboriginal and/or Torres Strait Islander Peoples.

- Specific symptoms provided such as cirrhosis, jaundice, swollen belly
- Health workers generally said they didn't see it
- Death, dying and pain
- Fear about it being the "C" word
- It's scary, it's the "C" word, cancer is scary
- Some stigma around liver cancer – they brought it on themselves with their choice of lifestyle
- People don't know that hepatitis B & C can turn into liver cancer if untreated
- People don't know how alcohol can lead to cancer
- Usually think when I see a patient: How much have they drunk, what happened to cause it?
- Denial – once they know, not going to do anything about it, seem to think it will go away...
- One health worker group spoke of how they try to reduce the impact with messages such as:
 - Drink light not heavy
 - Encourage safe drinking

Combined

Some people responded generally about hepatitis and liver cancer combined:

- Too shamed to tell
- Scary, means shorter life for me
- "Lots of information out there – but I don't pick up books"
- Death sentence – terrified
- Scared about how it is spread
- Private business
- Shame (about how you catch it) "everyone thinks hepatitis is AIDS"
- Been stupid to "get it"
- "They [community] don't differentiate the A, B and C of hepatitis". All the same until they need to learn about their diagnosis

There was a clear and more definitive shame and stigma around hepatitis C and to a lesser extent liver cancer. Significantly, as many people did not differentiate between hepatitis B & C, stigma also carries over to hepatitis B.

Liver Cancer and context

Whilst people discussed the stigma in relation to liver cancer, only two people had reported knowing a number of community members with liver cancer. Otherwise, community members and most health workers stated that they were not aware of people having liver cancer. In the context of other chronic illnesses, more common conditions in the community such as diabetes and high blood pressure were reported as taking a higher priority as they need to manage these existing conditions on a daily basis. These findings were also reflected in the literature.

The community discussions focused on viral hepatitis and liver cancer, given that was the focus of this exploratory study. However, the consistent message was that liver cancer was just as scary as every other cancer and there was less importance placed on the cancer type during the discussions.

Diagnosis

The most common comment in relation to diagnosis was an acknowledgement that signs and symptoms of hepatitis are not known or understood and not always present. Many community members commented about this whilst others commented that they were unaware and "just learning about it" as part of the consultation. The lack of signs and symptoms for viral hepatitis was identified as a factor in the delay in diagnosis.

Where the term Aboriginal is used in this report, it is inclusive of Aboriginal and/or Torres Strait Islander Peoples.

Testing

The Aboriginal health services that were consulted identified that they routinely screen for hepatitis B and C as part of their health assessments, however it was thought that general practitioners in the mainstream did not. One health worker group believed that Aboriginal people with disabilities and/or mental health issues were not asked about hepatitis.

Treatment

Treatment and hepatitis

There were mixed responses to the treatment and management of viral hepatitis. Some people were unclear as to which hepatitis could be treated and which required longer term management. Other people were unaware of the treatment and management of hepatitis in general. A number of community members and health workers were not aware that hepatitis B can be prevented (through immunisation).

A number of health professionals working with the Aboriginal community commented on factors that hinder treatment. In relation to Hepatitis C specifically:

- One Aboriginal worker shared the story of a woman choosing not to have treatment because it was too debilitating and she would not be able to look after her family
- One General Practitioner commented on the long term consequences of having viruses and waiting for new treatments. *“It is difficult to give clear messages in this context especially when people are thinking it might progress to liver cancer while waiting for a new treatment”.*
- In reference to the severity of the Hepatitis C treatment, one health worker summed it up by stating, *“It’s a huge commitment, you have to have all your ducks in a row, understand the treatment requirements and be financially and emotionally okay”.*

Treatment and liver cancer

Access for rural people was identified as a significant barrier to receiving treatment. Travelling to regional or metropolitan areas was prohibitive in terms of time away from family, costs, and the often times unfamiliarity with negotiating around the city. Long waiting lists in regional and metropolitan areas was also stated as a factor contributing to this barrier. It was noted that whilst chemotherapy was available (in some rural towns) hepatitis C treatment was not. Attending appointments with liver specialists often required travelling to Melbourne.

One community group discussed at length the need for more hepatitis clinics in Aboriginal Community Controlled Health Organisations (ACCHOs) and education for Board members to show that provision of a clinic does not condone injecting drug use.

Treatment and support

The importance of having a support person when visiting a doctor or specialist was emphasised by one health worker. *“A friend can be your eyes and ears”.* Another health worker suggested a case manager was necessary so that people receive adequate information that they can understand throughout their journey.

Treatment and lifestyle

Health workers identified that lifestyle factors for many injecting drug users with hepatitis C were a barrier to receiving treatment:

- *“If people don’t want to change their habits they are not going to worry about Hepatitis C”*
- *“Most people know they shouldn’t share needles, doesn’t stop them if they are desperate”*

Where the term Aboriginal is used in this report, it is inclusive of Aboriginal and/or Torres Strait Islander Peoples.

- Sharing – “but it’s okay because we are bro’s and cousins”.
- People have day-to-day issues to address if their life is out of control. This takes priority over managing hepatitis.

Treatment and emotional & spiritual well-being

Generational grief and trauma was identified as a factor around self-medication with drugs and alcohol. The message clearly was that this cycle of grief from the stolen generations and trans-generational grief needs to be addressed. This was seen as a vital factor in order to build resilience and reduce the use of drugs and alcohol with their potential link to viral hepatitis and liver cancer.

Culturally safe health system

The need for the health system to be more culturally safe so Aboriginal people felt comfortable attending appointments was raised by a number of people in each of the consultations.

The impact of institutionalisation continues to be a significant barrier for Aboriginal people attending large clinics. A couple of people shared their stories, not only of the stolen generations but the level of segregation that occurred prior to Aboriginal people being recognised as citizens and the discrimination that continues today.

Community members and health workers made numerous references to barriers to accessing hospitals. The impact of institutionalisation means large clinics become a big barrier. We “haven’t forgotten how things were in the older days...”

Suggestions for improving the health system

Designing a more efficient system around the client was suggested so that when someone comes in to the health service it coincides with the medical team so everyone is there on the same day.

A cultural plan for hospitals was also recognised as an important step towards improving cultural safety for Aboriginal clients.

Centrelink’s child immunisation payment was considered a positive incentive to increase immunisation rates for hepatitis B.

“Once engaging and in the door, you can make a difference... it’s about getting people in the door”.

Health professionals

The need for doctors to receive cross cultural safety training was identified a number of times by community members and health workers, “...think they’d had it by now hey?”

Many examples were shared about the discrimination that the Victorian Aboriginal community face from some health professionals and the reluctance to be continually subject to this within the health system in order to manage their health issues.

“... they think if you’re black and drink you can’t go to hospital – won’t get well treated.” “They know the way they get treated, by association and by experience of others – why bother.”

Aboriginal Hospital Liaison Officers were recognised as helping to “bridge the gap”.

“A doctor needs to sit there and listen, you need a particular kind of doctor”, and “Doctors need to have a cultural perspective in place”.

Where the term Aboriginal is used in this report, it is inclusive of Aboriginal and/or Torres Strait Islander Peoples.

Community awareness raising

The importance of the early years was acknowledged as helping to stop generational trauma. “If you change the life of a child you can improve their life for later”.

The community welcomed increased awareness and knowledge in relation to:

- Understanding hepatitis and the difference between hepatitis B & C
- transmission of hepatitis
- diagnosis, signs and symptoms
- management options

Members from each of the consultations spoke about the hepatitis and ‘Chopped Liver’ plays that they had seen and believed this was an effective way of getting messages to the community. These plays provided education and awareness in a visual form that also provided entertainment.

Messages (in whatever form) from community to community were also raised as a preferable way to increase knowledge and awareness.

The importance of community members supporting each other through support groups, camps, yarnning circles and get togethers was also identified.

The discussions also brought about an interest from the community about increasing their awareness and knowledge in relation to the cancer journey. Cancer Council Victoria was asked to hold a community forum to cover:

- prevention and screening
- genetics
- lifestyle information
- diagnosis, signs and symptoms
- treatment options and “how to clear it”
- support services and
- palliative care

There was interest in increasing community and health worker understanding of all cancers. An emphasis on having this information prior to a diagnosis, for self and family members was also raised.

Education - health professionals

The two community groups said they wanted clearer messages about how lifestyle can increase the risk of cancer. People spoke about being told to reduce their alcohol or give up smoking but not necessarily the link this continued use had on increasing their risk of developing cancer.

Professional development for doctors to increase their understanding of hepatitis was recommended. This supports the research that identifies a low awareness of the link between chronic hepatitis and liver cancer in primary health settings (NCHSR: 2012). Increasing doctor’s skills to communicate these messages more effectively with patients was also suggested as part of this training.

Increasing AHW knowledge (including healthy lifestyle teams and drug & alcohol workers) was also highlighted as beneficial to take opportunistic approaches to discuss lifestyle, information and education with the community.

It was suggested that hepatitis be included as an item on general health assessments.

Where the term Aboriginal is used in this report, it is inclusive of Aboriginal and/or Torres Strait Islander Peoples.

Summary

Consultations with members of the Victorian Aboriginal community and health workers confirmed findings in the literature that in relation to hepatitis B and C and liver cancer there is a shame factor that exists in the community. This is particularly around how hepatitis is transmitted.

Due to the lack of a clear understanding of the cause and symptoms (in an often times symptom free virus) of hepatitis B & C, there was a tendency not to differentiate between the two viruses.

Like in the non- Aboriginal community, there was no understanding of the link between chronic hepatitis and liver cancer amongst community members and many health workers.

A range of issues were raised in relation to treatment and the difficulty with the current hepatitis medication.

Access to liver clinics was raised as a major barrier for a number of reasons. This included distance to travel, doctors without cultural safety training or a health system that historically played a part on the impact of institutionalisation.

In relation to hepatitis C, health workers acknowledged that lifestyle factors need to be addressed for people who inject drugs before changes can take place. The need to address emotional and social well-being issues was also identified as a key factor.

The need for professional education for GPs and AHWs to increase their: knowledge of viral hepatitis; their communication around viral hepatitis; and hepatitis testing.

Community members were also keen to increase their knowledge and awareness in relation to viral hepatitis and liver cancer - the causes, symptoms, treatment and support for community.

Recommendations

To address the shame factor and misinformation in relation to viral hepatitis and liver cancer as raised during the community consultations, the project makes the following recommendations.

Community engagement and health professional education

Engaging community in awareness raising activities is integral for sustaining positive messages. Targeted education for health professionals to increase their knowledge and understanding of chronic hepatitis and the link to liver cancer in the Aboriginal community is also required.

- 1) Develop a community engagement approach when raising awareness of viral hepatitis, liver cancer and cancers that is culturally appropriate to the community. The community engagement and messages could encompass:
 - Informative and entertaining plays (the production of “Chopped Liver” was identified as a great way to instil messages with community)
 - Include messages within existing community and sporting events
 - Awareness raising forums
- 2) Deliver professional development training as part of continuing medical education. This would aim to:
 - Increase conversations, leading to testing by GPs and health nurses for viral hepatitis for the Aboriginal community
 - Increase knowledge and understanding of viral hepatitis and its relationship to liver cancer
 - Deliver cross-cultural safety training that is relevant to the Victorian Aboriginal community.
- 3) Develop a coordinated approach to address the community and professional education gaps identified in this report.

Systems Improvement

To specifically address some of the issues raised in relation to accessing treatment and the provision of culturally safe management of health conditions, the feasibility of the following recommendations should be investigated.

- 4) Ongoing support to health services to identify and record Aboriginal status for health professionals to address the issues raised in this project.
- 5) VACCHO/ACCHOs to consider including hepatitis items on health assessments.
- 6) CCV work in partnership with VACCHO to identify and address gaps in how people can be tested in a supportive environment
- 7) VACCHO/ACCHOs to consider inclusion of hepatitis clinics in their medical services.
- 8) Increase access to liver specialists in rural Victoria.

Where the term Aboriginal is used in this report, it is inclusive of Aboriginal and/or Torres Strait Islander Peoples.

References

- Australian Government Department of Health & Ageing, National Hepatitis B Strategy, 2010-2013
- Australian Government Department of Health & Ageing, National Hepatitis C Strategy, 2010-2013
- Australian Government Department of Health, National Hepatitis B Strategy, 2014-2017
- Australian Government Department of Health, Fourth National Hepatitis C Strategy, 2014-2017
- Australian Institute of Health and Welfare (2014) *Cancer in Australia: an overview 2014*. Cancer series No. 90. Cat. No. CAN 88. Canberra: AIHW.
- Butler, T. Lim, D. & Callander, D. 2011 National Prison Entrants' Blood borne virus and risk behaviour survey 2010, National Drug Research Institute Department, Curtin University, Kirby Institute & National Drug Research Institute.
- Cancer Council Victoria, 2013 Cancer in Victoria Statistics & Trends 2012, Cancer Council Victoria, Melbourne.
- Condon, J.R. Armstrong, B.K. Barnes, A. & Cunningham, J. 2003, "Cancer in Indigenous Australians: a review", *Cancer Causes and Control* Vol 14, pp109-121. 2003
- Davies, J. Bukulatjpi, S. Sharma, S. Davis, J. & Johnston, V. 2014 "Only your blood can tell the story – a qualitative research study using semi-structured interviews to explore the hepatitis B related knowledge, perceptions and experiences of remote dwelling Indigenous Australians and their health care providers in northern Australia", *BMC Public Health*, Vol 14, no 1233
- Department of Health, Koolin Balit: Victorian Government strategic directions for Aboriginal health 2012-2022.
- Fisher DA, Huffman SE, 2003, "Management of chronic hepatitis B infection in remote-dwelling Aboriginal and Torres Strait Islanders: an update for primary health care providers" *The Medical Journal of Australia* Vol 178, pp 82-85.
- Fourth National Aboriginal and Torres Strait Islander Blood-borne Viruses and Sexually Transmissible Infections Strategy 2014–2017 (Department of Health)
- Homewood, J. Coory, M. & Dinh, B, 2005 *Cancer among people living in rural and remote indigenous communities in Queensland: an update, 1997-2002*. Queensland Health, Health Information Branch, Information Circular 70.
- Hull, BP. Mahajan, D. Dey, A. Menzies, R & McIntyre, P. 2010, "Immunisation coverage annual report, 2008", *Communicable Diseases Intelligence* Vol 34, no 3, pp241-258
- MacLachlan J, Cowie B, 2012, "Liver Cancer is the fastest increasing cause of cancer deaths in Australians", *Medical Journal Australia*, Vol 197, no 9 pp492-493.
- McNally S, Latham R, 2009 *Recognising and Responding to Hepatitis C in Indigenous Communities in Victoria: A research project exploring barriers to hepatitis C treatment*, La Trobe University, Melbourne.

Where the term Aboriginal is used in this report, it is inclusive of Aboriginal and/or Torres Strait Islander Peoples.

Menzies, R. Tumour, C. Chiu, C. & McIntyre, P. 2008, "Vaccine preventable diseases and vaccination coverage in Aboriginal and Torres Strait Islander people", *Australia, 2003-2006, Communicable Diseases Intelligence* 32 (Supplement) SI-S67.

National Centre in HIV Social Research NCHSR, 2012, *A. Stigma and Discrimination around HIV and HCV in Healthcare Settings: Research Report.*: Australasian Society for HIV Medicine (ASHM) in partnership with National Centre in HIV Social Research, Sydney, Australia.

Olsen, A. Wallace, J. & Maher, L. 2014, "Responding to Australia's National Hepatitis B Strategy 2010-13: gaps in knowledge and practice in relation to Indigenous Australians", *Australian Journal of Primary Health*, Vol 20, pp134 -142.

Preston-Thomas, A. Fagan, P. Nakata, Y. & Anderson, E. 2013 "Chronic hepatitis B – care delivery and patient knowledge in the Torres Strait region of Australia", *Australian Family Physician* Vol 42, no 4, pp225-231.

Roder D, 2005, "Comparative cancer incidence, mortality and survival in Indigenous and non-Indigenous residents of South Australia and the Northern Territory." *Cancer Forum* Vol 29, no1, pp7-9.

Roder D, 2007, "Epidemiology of cancer in Indigenous Australians: implications for service delivery". *Cancer Forum* Vol 31, no 2, pp85-90.

The Kirby Institute 2014, *HIV, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2014*, University of New South Wales, Sydney.

Thompson Coon J, Rogers G, Hewson P, Wright D, Anderson R, Cramp M, 2007, "Surveillance of cirrhosis for hepatocellular carcinoma: systematic review and economic analysis", *Health Technol Assess* 2007 Vol 11, no 34, pp1-206

Victoria's Cancer Action Plan, 2008-2011, Victorian Department of Health.

Wallace, J. Pitts, M. Ward, J. & McNally, S. 2014, "Management of chronic hepatitis B in the Torres Strait Islands: an identified need for a comprehensive public health approach to chronic hepatitis B in remote Australian Indigenous communities" *Australian Journal of Primary Health*, Vol 20, pp273-277.

Wallace, J. McNally, S. & Richmond, J. 2007, *The National Hepatitis B Needs Assessment*, La Trobe University, Melbourne.